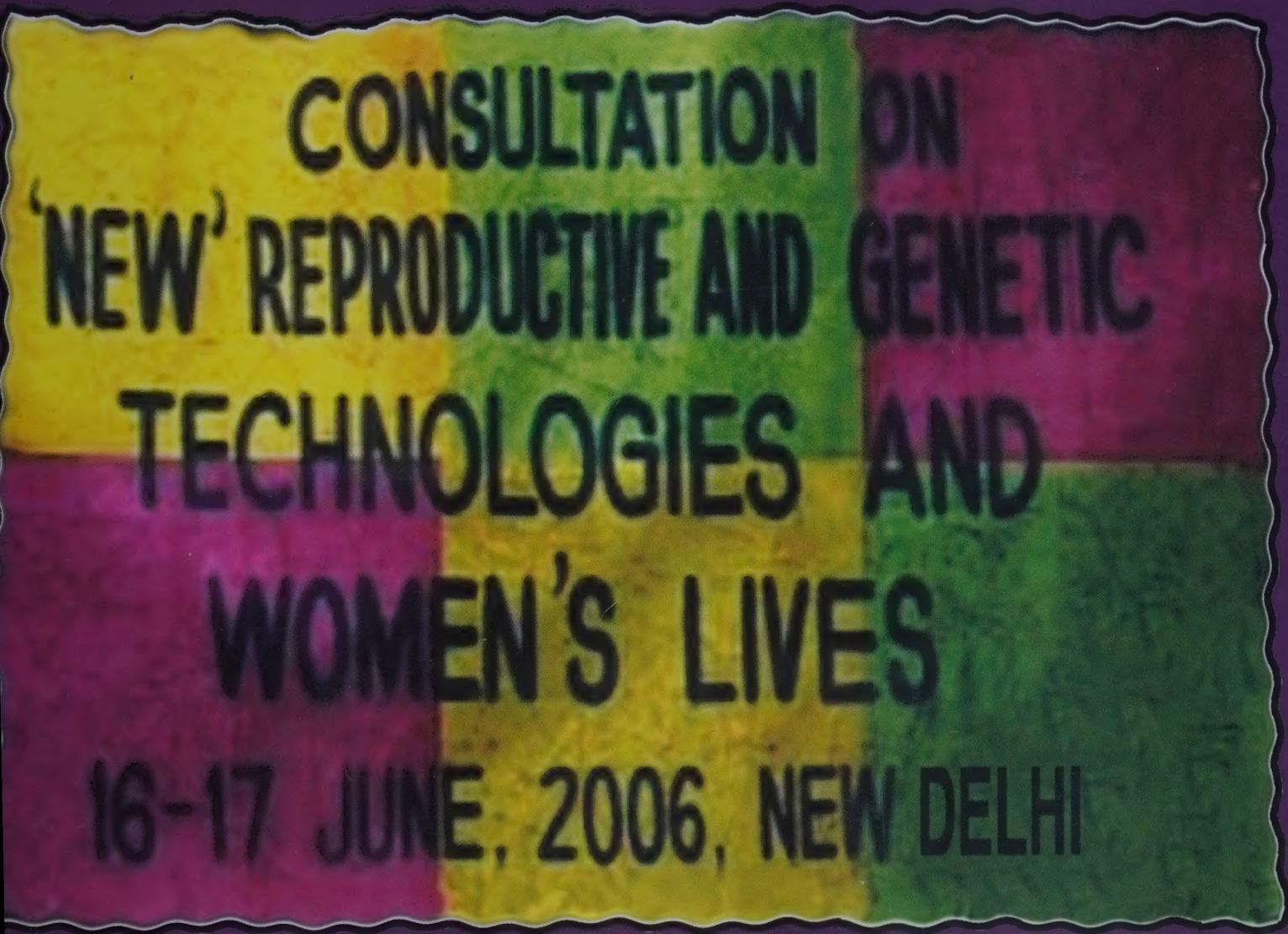
Consultation on 'New' Reproductive and Genetic Technologies and Women's Lives



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e-mail : chc@sochara.org

Consultation on 'New' Reproductive and Genetic Technologies and Women's Lives

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Sama

Resource Group for Women and Health

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B-45, 2nd floor,
Main Road Shivalik, Malviya Nagar,
New Delhi- 110017
Ph. No.:011- 65637632, 26692730
E mail: sama.womenshealth@gmail.com
sama_womenshealth@vsnl.net

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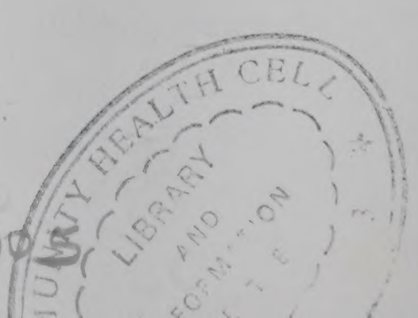

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Consultation on 'New' Reproductive and Genetic Technologies and Women's Lives

Introduction

Anuj Kapilashrami and Deepa Venkatachalam, Sama

Sama- Resource Group for Women and Health is a Delhi based women's group working from a larger perspective that links women's well-being with issues not only of health, but also those integrated with livelihood, rights, violence (societal, familial, communal and medical), and other larger issues that affect people's lives, especially those of women. In this regard, the work of Sama has evolved largely in the context of autonomous women's movement. Our activities include training community based organisations, action research, policy advocacy, policy monitoring and material production.

Sama has been engaged with issues concerning reproductive technologies ranging from sex selection to Assisted Reproductive Technologies (ARTs). Though some work has been done in this area, a systematic engagement with the issues related to ARTs and New Reproductive and Genetic Technologies (NRGTs) in particular is lacking. The understanding with regard to these issues is still very limited and inadequate. Such an investigation is urgently needed considering how quickly new genetic technologies and reproductive technologies are being developed and made accessible, in large part because of the increasing impacts of globalisation and privatisation.

It was in this context, that Sama initiated work on a research study in December 2004, to examine and investigate how ARTs touch women's lives and to enable a critical understanding of ARTs, especially regarding their implications- social, ethical and physiological, on the lives of women.

Initially the Consultation was planned as a forum to share and discuss the findings of Sama's research study, but on reflecting on the complexity and multidisciplinary nature of the issue and the diversity of perspectives that emerged, it was decided that the ambit must be widened. The fundamental aim of the Consultation is therefore to bring this issue in the arena of public debate, thereby raising awareness about ARTs and their numerous implications, potential drawbacks and to collectively generate strategies to address the issue.

Placing the Consultation in the Present Context

Presenter: Sandhya Srinivasan

Sandhya Srinivasan is a freelance journalist and consultant. She writes on issues of health and development for various publications and websites, and was a Panos Reproductive Health Media Fellow in 1998. She is a consultant on health and population for a website on issues of development, www.infochangeindia.org. She is also the executive editor of the Indian Journal of Medical Ethics and member of the editorial board of Developing World.

Presentation

The field of Assisted Reproductive Technologies (ARTs) has been rapidly growing over the past ten years. It is essentially unregulated and in addition, ARTs are accessible to many sections of society and are no longer an option only for the rich. There is increasing investment being made in this highly competitive field and there is a need to look at the direction in which all of this is heading.

Some fundamental questions that could be considered during this Consultation:

1. What is the relationship between contraceptive technology and fertility technology? How are they conceptually linked?

2. What is the public-private partnership in the field of In Vitro Fertilisation (IVF), especially the evolution of this relationship since the 1980s? How these two sectors will be linked in the future?

3. What is the relationship between fertility technology and public health? For instance, basic primary health services such as tuberculosis diagnosis and treatment services aren't always available to those who need it, but high-tech fertility services are.

4. How has this industry been regulated and how will it be regulated in the future? How are the issues that are raised by practitioners being addressed?

5. How have perspectives on existing issues evolved over time? For instance, until recently (the last 10 years) the fertility industry was not seen as a big concern in India, because it was not seen as a problem or major need. But now it is being considered as necessary. Does this mean that fertility is seen as a need and a right? My personal view is that fertility is not a priority.

6. The last 20 years have witnessed various campaigns against sex selection. But other forms of selection are not being discussed. Is it all right to oppose sex selection but not to look at the other pressures on women, or other selection criteria?

These issues and many others need to be considered and the Consultation will provide a starting point for these dialogues.

Tracing the History of the Indian Women's Movement's Engagement with Reproductive Technologies

Presenter: Manisha Gupte

Manisha Gupte has been part of the women's movement since the mid 1970s, and is an activist in the health and civil rights movements in India. In 1987, she co-founded MASUM, a rural women's organisation based in Pune, and has been its co-convenor since then. She spent a year in the Department of International Health at the Johns Hopkins University, Baltimore as a visiting fellow. She is actively associated with pro-people and progressive organisations regionally, nationally, and internationally as an advisor, trainer or board member.

Presentation

We can begin this debate by asking why these technologies were developed in the first place. The interlinked history between women, science, technology and inherent values in technology is a complex and convoluted story. It thus becomes very important to explore some of the myths around these technologies today. Some myths and confusing issues that need to be addressed are:

The first point to be made in this context is that ART treatment is not about actually treating/curing infertility. It doesn't make a woman fertile. It sometimes produces a baby, but it certainly doesn't treat the problem. By contrast, adoption too is not a treatment for infertility but it has a 100 per cent success rate.

Childlessness is inappropriately equated with infertility. There are many instances of childlessness that are not cases of infertility. For example, in India a woman is sometimes considered childless if she has no sons, but she does have children and is certainly not infertile. A woman whose child has died is also childless, but here again she is not infertile.

We also need to deconstruct the myth of bonding and biology. The common perception is that affection and bonding comes only from a biological connection. For

this we need to take a closer look at the definition of 'parentage'. We also need to look at various views that are associated with infertility and childlessness, including the perception and connection between masculinity and bearing a son – that if a man does not has a son, then his masculinity is somehow less or is challenged. This technology that gives a sperm/egg to someone else in a caste society has an element of subversion.

There is the perception that a woman's womb is someone else's (her husband's) property and the perpetuation of this concept of property is further enhanced by the social effects of patriarchy and capitalism. It is not the women's reproductive structure that matters; her womb belongs to whomsoever she is married to. This is illustrated in the Mahabharata, where none of Kunti's sons were fathered by Pandu, but they were called Pandavas nonetheless.

Infertile women have not been a point of concern for the women's movement. Infertility, involuntary motherhood (not wanting to be a mother but being forced to, or wanting to but not being able to) should also be the rallying points for the women's movement. We must also address the myth that bans solve problems and that bans should be enacted to control a technology. Bans are not the most effective way of dealing with things, and often have unexpected repercussions and backlashes.

The question of resources also needs to be clarified. Would health care be more refined if there were enough resources? What is the relationship between access to technology and limited resources? We need to ask for more resources for the health sector. And if such resources were made available, which technologies would be accepted, and which not? We need to make a wish list, based on the properties and needs of the society.

We can't deny women medical interventions if they want them. We must instead ask some fundamental questions, such as, what kind of interventions do they want? Does this violate someone else's right? Whose reproductive material (egg, sperm) will be used? Does this help her? There are many more similar questions to be addressed. In 2006, these issues must be discussed differently than they were in the 1970s. What are the parameters of negotiability? And once accepted technologies have been decided upon, there should be no discrimination in terms of availability of these technologies to private upper class or poor public sector. In our approach, and campaigns, there are certain issues to be avoided that often act as traps or dogmas:

- We need to avoid essentialising women, reproduction and motherhood.
- We should work to avoid the sacredness of birth and death, as most controversial technologies are at these ends of the spectrum of life.

- We must try to avoid the argument that interventions in nature are a problem and that any intervention is bad. For example, glasses and hearing aids are also interventions.

- Avoid the idea that there is only one way to think, one argument. We need to be challenged by other progressive movements. And this also means avoiding the departmentalisation of the women's movement.

- The debates in 2006 need to understand the right to dignity and personhood.

There are some strategies we can utilise:

- Expose opportunism by setting 'markers' that expose rhetoric and that help us identify others speaking the same language but have a very different and perhaps undesirable ideology.

- Expose the capitalistic exploitation of women's consumerism and the commercialism of women.

- Increase choices and options. It is also important that we do not lock ourselves into a particular stance.

Session 1:

Assisted Reproductive Technologies (ARTs)

Moderator: Chayanika Shah

Chayanika, is an activist in the women's movement and a part of FAOW (Forum Against Oppression Of Women) and LABIA (Lesbians And Bisexuals In Action) in Mumbai. She has been working on concerns pertaining to sexuality rights and has also co authored "We and our fertility" a book looking into the entire range of reproductive technologies from the point of view that there is no fundamental difference between two kinds (contraceptive and conceptive) of technologies. Chayanika teaches Physics at Mumbai University.

Introduction

In this session we will be looking at the medical and social implications of issues of infertility and ARTs, and how these issues impact women's and men's lives.

Though we are using the term ARTs, we should perhaps reflect on the language and terminology used. When we speak of "infertility management" we are talking about assistance and in a way reiterating that there is a constant need to reproduce and therefore for assistance to people who are not able to do so. In terms of contraceptive technologies and ARTs, we can also reflect on aspects that the language may be hiding what the technology is trying to do.

We have a range of issues laid out before us. In the last few years we have had discussions about contraception and hazardous contraceptives, fertility control, birth control. Various terms have been debated and discussed but seldom have we looked at the flipside of the Reproductive Technologies and that is the ARTs. Beginning with these two research presentations, we will place the agenda completely on the table. In doing this we will try to obtain a clearer picture of the state of assisted reproduction (in particular IVF) in India, and how people are dealing with infertility and reproductive technologies in India.

Assisted Reproductive Technologies: Medical and Social Implications for Women

Presenter: Manjeer Mukherjee

Manjeer Mukherjee is pursuing her doctorate in Sociology from Jawaharlal Nehru University, New Delhi. She works with Sama and she is currently co-coordinating an action research project on the medical and social implications of Assisted Reproductive Technologies on women, especially artificial insemination, in vitro fertilisation and surrogacy. She has been actively engaged in the civil society deliberations around sexual and reproductive rights and right to health care in India.

Presentation

This presentation is based on Sama's study of ARTs's impact on women in India, and how ARTs are seen as a solution for women's problems. Given the proliferation of infertility clinics without guidelines, we felt the need to document what women and providers of these technologies have to say about infertility and ARTs, also including a look at issues such as surrogacy and adoption. We also interacted with activists who are a part of various movements, in order to understand their concerns and engagements with issues of ARTs.

The objective of the present research has been to unravel the social, medical and ethical implications of ARTs for women. The specific focus of the research was therefore:

- to look at the context in which women use ARTs, and the costs (physical, social, economic) incurred,
- to explore the perspectives of the providers on the 'treatment' and its 'users',
- to understand women's experiences and their perceptions of the 'treatment', and
- to review the status of regulation, guidelines, policy at the nationallevel and inherent ethical dilemmas

The methodology used:

The research had two essential components: At the theoretical level, a systematic exploration of the field of ARTs was undertaken through:

a) a review of existing literature; documents, articles, feminist writings, books and journals.

b) an analysis of advertisements, newspapers, websites, popular magazines, and the brochures of ART clinics.

c) a review of the ICMR National Guidelines for "Accreditation, Supervision & Regulation of ART Clinics in India, 2005".

At the empirical level, primarily qualitative research methods like systematic observation and in-depth interviews were undertaken with the providers of these technologies (gynaecologists, infertility specialists, embryologists) and with women undergoing these procedures of ARTs (Intra-Uterine Insemination, In-Vitro Fertilisation, Intra Cytoplasmic Sperm Injection). This was helpful to understand the perceptions of providers and also the experiences and perceptions of women using these technologies. Checklists with open-ended questions were developed to facilitate the interviews.

A similar method was followed for the interviews with women's rights activists, health activists, disability rights activists and sexual rights activists to understand the debate and engage with the concerns about ARTs across movements. We also interviewed legal rights and human rights activists to understand their concerns regarding this issue.

These personal interactions helped us gain a better understanding of the development and proliferation of ARTs. Given the fact there was not much secondary literature available in the Indian context, these interviews and discussions were immensely enriching and educative.

Interactions with National Institute for Research in Reproduction (NIRR) and Indian Council of Medical Research (ICMR) officials and visits to adoption centres, surrogate agents and public health institutions were also carried out as part of the research.

During the course of the study, 23 providers and 25 women receiving treatment were interviewed. The study areas chosen for the research were Mumbai, Delhi and Hyderabad. Delhi and Mumbai were chosen because these metros have some of the most prominent clinics and providers in the field of ARTs and cater to a population not only from within the city and the country but also from overseas. Hyderabad was chosen in order to understand the extent of infiltration of these technologies in a non-metropolitan city. The choice of the study area was based on the availability of human resources in a particular city, knowledge of the local language and familiarity with the city.

Profile of Providers

Among the providers interviewed, four were men and 19 were women. Most identified themselves as 'infertility specialists'. Others were gynaecologists or embryologists with various specialty areas in ARTs. Most of the providers had more than 10 years of experience.

Responses of Providers

We asked the providers questions regarding some major concerns in ARTs. Despite a wide range and variety of responses, some common comments were articulated, which revealed the underlying attitude towards the issues of ARTs. Some of these will be brought out in the presentation.

1. The kinds of techniques that are not offered?

Some providers did not offer certain treatments due to specific philosophical or moral reasons, such as refusing to use sperm that is not the husband's, or refusing surrogacy treatments. Most did not have an egg donor program.

2. Who is accessing 'treatment' and procedures from these providers?

Most said the treatment is accessible to all classes, not just the rich or upper classes. The general consensus was that because couples want to have a baby so desperately, they will find a way to pay for necessary procedures no matter what the cost.

The other strong attitude was a default reference to married couples, and little credence given to 'treatment' for single or divorced women.

There was also a wide range of opinions as to whether post-menopausal women should be provided 'treatment'.

3. Reasons for infertility

The providers listed a number of physiological reasons (tubal blockage, genital TB, low sperm count/mobility, untreated STDs) as well as environmental and lifestyle factors (such as stress, promiscuity leading to STDs) that tend to put the 'blame' for infertility more on the women.

4. Providers' perception of men's/women's reactions to their diagnosis/ treatment

There was an emphasis on how men deal with their own infertility.

Stereotypes also arose about how certain 'classes' in society deal with their infertility (i.e., educated versus uneducated).

5. Characteristics of donors are requested by 'patients'

Most of the users focused on characteristics that are perceived as being most 'desirable' in society: fair skin, healthy, well educated. There were also requests that donors resemble the parents in order to minimise the artificiality of the process.

6. Donor characteristics matched by the providers

Providers generally said they tried to match donors according to physical features, hair colour, etc, but they also mentioned that they tried to use donors from 'good families'. Their responses underlined a belief in genetic essentialism and the impression that good and bad genes can be identified according to socio-familial backgrounds.

7. Adoption seen or suggested as an option

Generally, providers saw adoption only as a last resort for couples, either due to lack of success with the ART process, or lack of funds.

8. The social pressures of infertility

The providers recognised the great pressures on couples/women to have children, which makes them 'desperate' to access these technologies. There is no attempt to question this social pressure, though there is a recognition that this pressure of child bearing falls on women because of "the male dominated society". What is important is that there is an attempt to reinforce this social pressure by projecting these technologies as providing "the solution to those couples who are desperate to have their own children".

The brochures from the providers show that this social pressure is taken advantage of in marketing the technologies and reinforcing this idea of 'making a dream come true'. The brochures speak of attempts at normalising and naturalising "the urge" and "instinct to procreate" as universal and that "every couple has a biological right to have children of their own".

9. Counseling provided to 'patients'

Counseling is provided to help deal with the stress of infertility as well as the 'treatments', donation of egg/sperm, information about the procedures, and side effects.

However, the number of providers actually giving such counseling was very low, and clinics generally provided counseling just in one or two of the aspects mentioned above, but, rarely on all relevant topics.

10. Counseling on side effects of drugs and complications of procedures

Although most clinics seemed to discuss some aspects of the possible side effects, it varied widely and was inconsistent among providers. On probing further, providers said that they either try to do a risk-benefit analysis or they tried to justify the side effects as part and parcel of using any kind of drug, (e.g. for aspirin) or by individualising the side effects and putting the onus on the woman.

11. The maximum number of cycles recommended (IUI/IVF) and number of eggs retrieved and implanted in IVF cycles

The maximum number of IUI cycles ranged from 3 to 6, and IVF cycles ranged from 3 to 7, with a maximum of 10. Egg retrieval ranged from 7 to 16 eggs per donation, and embryo implantation ranged from 2 to 5 per cycle, but usually 3 are implanted.

12. The 'success rates' given, in particular the implantation rate as compared to take-home baby rates

The average implantation rates given were about 10 per cent to 40 per cent. The average actual take-home baby rates given were about 20 per cent to 30 per cent. In the brochures of the clinics the success rate given was in fact typically the implantation rate, not the take home baby rate.

13. The costs of the various techniques

While costs ranged widely, on average the IUI procedure was quoted from Rs 1000 to Rs 10,000. The IVF procedure costs, including all drugs, went as high as Rs 1,00,000.

14. The cost of treatment be reduced

Providers felt that the government should reduce the costs of the drugs, and help more with family planning programmes.

Results from Interviews with Women

We asked the women questions relating to major issues of infertility, ARTs and their lives.

Profile of the women interviewed

All the women interviewed were either going through IVF/IUI or had been advised to do so. 80 per cent of these had never conceived prior to the treatment. They were all married and between 22 to 46 years of age, with most being between 30-40 years. Most of the women were or seemed to be from middle class background, most being

'housewives', and others were professionals in various fields. All were Hindu except for one Muslim woman.

Some key areas that emerged from our interviews with women:

1. The social context of seeking assistance

Women spoke about the pressure they felt from their families and society, as well as the pressure they put on themselves. It is difficult to draw lines between the notions of an individual woman's conscious wish to have a child and the socialisation which makes women feel "incomplete' unless they have mothered a child after marriage.

2. The notion of motherhood

Women expressed motherhood in terms of the essential process of giving birth, as well as the natural progression after marriage. There was an inescapable sense of the essentialism of motherhood as the normal, natural role for women.

3. Women's views on adoption

Adoption was generally seen as a last resort, if everything else fails. They expressed concerns regarding the community knowing that it's not your own child, and the personal feeling as well that it's not 'your child'.

4. Contact between users and providers

Most women sought some kind of assistance within the first year of trying to conceive, some waited up to three years. The indicator to define 'infertile' is ambiguous.

The first step most of the women took was to see a gynaecologist, and others went to see other kinds of doctors such as infertility specialists or Ayurvedic doctors.

5. Pattern of Treatment(s)

Many of the women had gone to multiple doctors and attempted a variety of treatments.

6. Diagnosis for not conceiving

Women were often given conflicting reports regarding the reasons for their infertility, and often did not really know what the actual problem was.

7. Information provided to the women by the providers on the procedures, side effects, success rate.

The proportion of women given information about the procedures or side effects was very low (about 4 per cent), but the proportion that were told of the success rate was much higher (about 30 per cent).

Some women felt that information regarding success rate should not be provided. Some also articulated that they were not given information as most of the times the doctor was busy or they themselves were hesitant to ask. Moreover, it was given to them in a way that they could not relate to it or understand it.

8. Side effects of drugs taken or complications of the procedures as experienced by users

About half the women said they had some kind of side effect from the drugs, but often didn't identify them as negative. There seemed to be a generalised understanding among all users to look at the side effects as something minor and as a necessary part of going through the treatment. Moreover, there has probably also been a risk-benefit analysis, comparing the risk of complications with the risk of not having a child. This might have prompted them to negate or attribute very little importance to the side effects and complications and resolve to continue with the treatment despite all these.

9. The impact of the 'treatment' on life (general routine, work pattern, sexual life)

Women spoke of how time-consuming and disruptive the clinical procedures are in terms of time spent at the clinic or travelling to it. The demands on the women's sexual life were frustrating due to the imposed 'schedule', and that often the knowledge of infertility reduces those demands.

10. The success of the procedures

Fourteen women were undergoing IUI. Five women conceived, and the rest were repeating the process for up to the eighth time. Four of the women underwent IVF, out of whom three became pregnant. Other women were in the process of recommendations or various treatments and had often gone through IUI or IVF or IVF-ICSI multiple times. Only one of them became pregnant.

This paints a picture of great investment of time and money and emotion on the part of the women/couples, with very limited rates of success.

11. Costs of the procedure (and 'hidden' costs also – diagnostics, travel, etc)

Average IUI costs were stated around Rs. 5000-6000 per cycle. But this can be as much as Rs. 30,000 – 40,000 if diagnostic and other 'hidden' costs are included. Similarly, average IVF costs were around Rs. 1 to 1.5 lakhs, but with the hidden costs it can be as much as Rs. 2,00,000.

The cost of the procedures, which was generally quoted by the providers, did not take into account the cost of the diagnostic tests like laparoscopy, ultrasound, consultation fees, drugs and injections etc. Also, it did not calculate the money spent on travel, staying in the city if the woman is coming from a different city, the cost of loss that one suffers in one's own business. These hidden costs of the treatment were being highlighted by users while talking of the cost involved.

12. Women's experiences and perceptions of the 'treatment'

Women generally used words such as "tiring", "frustrating", "mentally exhausting", "draining", "dejection", and "desperation" to describe their experiences. Some women said that at first it is tense, but then after a while it becomes routine.

One woman said: "They say that science has progressed but I don't understand with my little knowledge how it has progressed. Even during Mahabharata, Pandu, Dhritarashtra and Vidur were all sons of Vyas Muni—isn't it so? Even all of Pandu's children are born from different Gods— I am really at my wits end".

These are preliminary findings, without complete analysis of trends, etc. The final analysis still remains to be done. The report will soon be published.

Session 1, Presentation 2

The Pro-Natalist Imperative: Infertility, Stigma and Marginalisation in the Age of Assisted Conception in India

Presenter: Aditya Bharadwaj

Aditya Bharadwaj teaches Medical Sociology at the School of Social and Political Studies at the University of Edinburgh. His principal research interest is in the area of New Reproductive, Genetic and Stem Cell Biotechnologies and their rapid spread in diverse global locales ranging from South Asia to the United Kingdom. He has undertaken research that examines the proliferation of embryonic stem cell technologies in India and the United Kingdom.

Presentation

This paper looks at some of the stigmas involved with infertility, and with seeking treatment (primarily IVF) in a pro-natalist society. By interviewing infertile couples from a wide range of backgrounds, as well as clinicians, the experience and stigmas of infertility and as well as the stigmas of receiving IVF treatment is examined, and the pro-natalist imperative role in stigma has been explored.

Methodology

Over 15 months in 1997-1998 and then again in 2003-2004, data was collected from 43 open-ended interviews with individuals and couples attending three IVF clinics in Delhi, Jaipur and Mumbai. In addition, interviews were conducted with clinicians.

The couples interviewed came from a range of socioeconomic backgrounds, from farmers to industrialists.

Some Results

The affluent and poor alike cannot escape stigmatisation caused by infertility in a society governed by a pro-natalist imperative. Stratified reproduction is imposed by the pro-natalist structure, which cuts across social, economic and other boundaries. The stigma created is so stifling that few can afford to accept a childless family or open adoption. At the same time few people can also afford the heavy financial burden of fertility treatment such as IVF, while socially they can't afford not to. As a result, couples' lives are 'reproductively disrupted' in a variety of ways.

Infertility and Stigma

The infertile couples interviewed often retreated into their own world due to the social ostracism caused by the stigma of infertility. Medical treatment becomes the only option due to the extreme social discomfort, pressure and rejection they face.

Besides the well-known stigma of ostracisation, there is also the quieter yet painful stigma of avoidance - the 'curse' of the barren woman, an ill omen. Other women try to avoid contact with the infertile woman for the fear that her barrenness will make them or others barren.

There is a stereotype that men abandon their wives upon infertility, but in this research this was not been found to be true. Despite the stigma of infertility, the men remained with their wives even through the long, drawn-out process of IVF treatment. Men get equally stigmatised when they choose to stay with barren wives rather than support the patriarchal image of remarrying in order to have a child.

Stigma can penetrate the otherwise fixed social boundaries. 'Stigma-management' doesn't work well in India, due to lack of privacy and limited choices.

Medical Marginalisation

Couples described the dehumanising of women through the ART procedures. They expressed feelings of disappointment, anger and betrayal at the doctors for the nature and quality of their treatment. However, couples persisted in getting treatment

despite the great cost it involved and the repeated failure. Treatment/IVF is seen as a face-saving device, which is often unaffordable but yet cannot be ignored. But many of the couples were in dire financial straits as a result of pursuing the IVF treatment.

The 'reproductively disrupted lives' in this research are a result of the entrenched gendered reproductive divide in the society. In this case, the social stratification is between the fertile and infertile. The stigma of infertility is a great leveler, occurring regardless of a woman's socioeconomic or social status. Even as these infertile couples often cannot afford treatment, they must attempt the treatment in order to escape oppressive familial and social pressures, in an attempt to escape the stigma.

Session 1: Discussion

Comments from the Moderator

The uniqueness of Aditya's presentation is that there are conversations with the couples, and perhaps more importantly with the men who are partners of women undergoing treatment. It is an effort to hear other voices apart from the women.

Questions and Responses

Q: Did you probe into issues of caste? Does caste make a difference?

Response:

Aditya: The couples belonged to different castes, a whole range of castes. They were not all from higher castes. Preference for a caste-based donor was not a primary requirement so long as it was kept a secret.

Q: What were your findings about dynamics of nuclear family versus joint families? There is some evidence about violence and other issues being worse in nuclear families as opposed to joint families. Is anything like this also reflected in terms of receiving ART treatments?

Response:

Aditya: Even people living in nuclear families talked about pressure coming from people outside the family. So the type of family didn't have much impact on getting treatment. The main issue was about access to treatment and how the women wanted to disclose this fact to the family. There were concerns about the source of the sperm, would the baby belong to the family, etc. No particular aspect regarding nuclear vis -a –vis joint family came out.

Q: Did the question of having the 'perfect child' come up? Usually there is more concern about just 'having a child', but were any questions asked regarding counseling for 'patients' about disabled children?

Response:

Manjeer: Counseling about the 'non-perfect' child was not asked about.

Aditya: Regarding the need for a 'perfect child', one woman said: "Even if it's a girl, I don't mind. Just get me pregnant." The stigma of not bearing a child is more crushing than the need to have a son. Disabled children did not come up as an issue. PGD was not an issue at the time of the study.

Q: Is the sex of the baby part of the anxiety people were experiencing around conception? Were any providers offering sperm-sorting technology to assure that the sex of the child can be chosen?

Response:

Manjeer: Only one of the couples interviewed said that they had to sign a form saying they would accept either a boy or girl otherwise it didn't come up.

Q: What in the research supports the assertion that men stick with their wives? Is it only couples going for IVF? What about those who do not go for treatment? And is it abandonment of wives or only separation from them?

Response:

Aditya: Among the 54 interviews, the average duration of marriage was 10 years. Seven of those years had been spent seeking treatment. Even though the sample size may be small, IVF seems to become a filter through which only the strongest relationships last.

Q: Can you elaborate on why adoption is not an option in India?

Response:

Aditya: Adoption is not an option because of the problem of secrecy, and also because people don't want someone else's child. In IVF, at least there is some genetic connection, and there is a visible pregnancy.

Q: In the Pro-Natalist paper, what was the class background of the couples that stuck together in your research? Were they middle class?

Response:

Aditya: The class background of respondents ranged from industrialist to farmer. But they were all 'working class' meaning they had something to sell, mortgage, etc. There were other families that had no material resources. In addition, among these couples that do go for treatment, there is constant bargaining between doctor and patient. There was also no geographic correlation with the clientele regarding the location of the clinic. 'Patients' travelled long distances to different states.

Q: Most analysis seems to be focused on the IVF clinics. What about interactions that lie outside the IVF clinic, with other doctors like the gynaecologist who is the first doctor seen? Looking at health-seeking behavior, decisions are often products of complex negotiations between family, community, etc. Is there something specific about IVF that excludes these other interactions, or are we being too focused on the IVF provider-patient relationship?

Response:

Manjeer: Other doctors were not a focus of the study. But among some providers a philosophy emerged – that it is wrong to find out why a couple was unable to have a child. The focus instead should be on getting the woman pregnant.

Aditya: Within a family, even the doctor will manipulate tactical alliances. There are behaviors such as collaborating to hide treatment, secrecy, family members recruiting donors, etc. and working to make the conception look 'normal'.

Comments from Participants

- Dr. Bharadwaj's paper has a strong voice of the couples, including the men, not just looking at women's voices.
- What are the political implications if there is this equality of suffering? In terms of organising women's health, are there possibilities of cross-class alliances?
- The use of words such as 'barren' etc. is objectionable.
- Adoption can occur after only three months, one doesn't have to wait for one year. The mother has 90 days to reclaim the baby. Acceptance ratios for boy and girl child are equal. Adoption has class and caste bias, because the poor cannot show 'capital' and the ability to support the child. Only Hindus, Jains, Sikhs, Buddhists can adopt in India. All other religions can only take in children as guardians. Single women can adopt, but women who are disabled and single cannot.

- Regarding the providers' interviews, it is worth speaking to doctors the women go to before going in for ARTs, such as gynaecologists.

- Avoid the essentialism of motherhood being related to marriage. It's important to document how motherhood can exist outside the notions of marriage and family. These days, in small and obscure ways, these things are being thought of in different contexts. We need to look at other ways to 'be mothers'.

- Out of 23 providers interviewed in Sama's study, 19 were women. Were their perspectives different from the men's? Has the involvement of women in this field made any impact? If not, it's important to reflect on this.

- We also need to explore answers for some questions like, the exact rate of infertility. Is it on the rise in this country? How many patients really require ARTs? Regarding side-effects – the study asked about short-term side effects. What about long-term side-effects such as cancer?

Comments from the Moderator

These discussions are important and there are many issues that make us uncomfortable. The use of terms like 'barren', 'infertile', 'childless 'is one of these issues. These studies are very limited, involving 25 women, 43 couples is a very small sample. Even if we don't want to accept science as a demi god there has to be some methodology that is necessary to follow. Therefore, when we make generalisations we have to be little careful. These are questions that will come up over and over again. How will we understand what women go through, what are the pressures on women and men when they are pushing themselves to go through these procedure, where the set up is commercial, and people are out to make money. Maybe, we need to look at the people who have decided not to use the technologies, or tried and given up. There is a lot we need to look at and this is just the beginning.

Session 2

Misuse of Technologies and Techniques

Moderator: Indu Agnihotri

Indu Agnihotri is a Senior Fellow with the Centre for Women's Development Studies (CWDS). Prior to this she was teaching History in University of Delhi. She has been actively involved with the women's movement in Delhi since the 1970s and is a founder member of All India Democratic Women's Association (AIDWA).

Introduction

This session will raise more issues on ARTs. The previous discussions had a large focus on 'motherhood' and 'childlessness', while this session will attempt to take a look at concerns where technology assists in getting 'desirable' (sons and 'normal') children.

It is important to look at the role of the State is in all of this. In many issues, there are grey areas regarding laws, enforcement, loopholes, etc. Even when there are laws, there are so many issues of subverting the law and difficulties in implementing the law. This brings us into confrontation with the world outside the family, such as the collapse of the health care system, public versus private health care, etc.

Session 2, Presentation 1

The Business of Sex Selection: The Ultrasonography Boom

Presenter: Vineeta Bal

Vineeta Bal is on the faculty of National Institute of Immunology, Delhi. She is a member of Saheli, and has been associated with it for more than 10 years. She is a physician by training and a researcher in biology/immunology by profession.

Presentation

In 2002, amendments were made to the Pre-Conception and Pre-Natal Diagnostic Techniques (PCPNDT) Act of 1994 to regulate and prevent the misuse of sex selection technologies. However, despite the law, sex determination continues, causing an ongoing decline in the sex-ratio. In order to study this problem and determine a

course of action, in 2004 the Ministry of Health and Family Welfare conducted surveys in various states to study the functioning of Ultrasonography centers, since Ultrasound was believed to be the most widely used technology for sex determination leading to selective abortion. These surveys found a direct correlation between sex-ratio and the number of registered Ultrasound clinics.

One very important finding from the surveys was that "The richer the district, the poorer the sex-ratio". Richer states have more Ultrasound centers, and more Ultrasound centers mean poorer sex-ratios.

- Maharashtra survey – Western Maharashtra, with Mumbai and large rich cities, accounts for more than 78 per cent of Ultrasound clinics registered in the state. This region also had the worst sex-ratio in the state, compared to poor and tribal districts in the state, which had the fewest Ultrasound centers and the highest sex-ratio. Districts with more than 100 centers had a distinctly lower child sex-ratio than districts with less than 100 centers.

- Karnataka survey- Four districts out of 27 accounted for more than 70 per cent of the Ultrasound centers. In these four districts, the child sex-ratio was the lowest in the state.

- Gujarat survey – 95 per cent of centers were owned by the private sector. And of these, less than 50 per cent have qualified persons operating the Ultrasound machine.

Even though surveys in other states did not reveal a clear pattern between number of Ultrasound centers and child sex-ratios, the surveys showed that the centers were not functioning according to guidelines in the amended PCPNDT Act. They also revealed that Ultrasound is indeed the technology most widely used in sex selection, and it is proliferating most in the richest states.

An analysis of the reasons for widespread use of Ultrasound technology would facilitate the development of a strategic action plan, including the economics contributing to the rapid increase in availability of Ultrasound equipment.

The economics of social prejudice

There have been simultaneous growth of the middle class, in privatisation of health care, in domestic production of necessary technologies (which may directly increase the availability of ultrasound diagnosis and sex selection), while at the same time import duties have decreased (thus increasing incentive for importing Ultrasound machines). These cumulative economic factors point towards some of the reasons for the boom in Ultrasound clinics.

To cite one example, there has been a disproportionate increase in the manufacture of Ultrasound scanners in India over a period of 15 years (compared to other electronic medical equipment). There has been a 33-fold increase in Ultrasound scanner production, compared to almost no growth in other devices over the last 15 years. Coupled with this is the high demand for Ultrasound scanners. We see much higher market growth rates compared to ECG and other medical technology supplies. This is not to make implications about the usefulness (or lack of) ECG machines. The point is that they are both equally useful, but the growth rate for Ultrasound machines is disproportionately higher.

Such economic factors lead to the proliferation of sex determination technologies and the social issues of sex selection augment this proliferation. It is not merely a question of technology, since in the 1980s Amniocentesis also made sex selection possible. But, the ease of use is a major positive point, which makes a technology successful and widely used. Ultrasound is much easier, less expensive and is non-invasive, unlike Amniocentesis, or even the new PGD technology, which also allows sex determination. Thus Ultrasound is much more acceptable, more affordable, and is seen to be spreading to lower castes and other religions as well.

The campaign against sex selection and sex selective abortions faces major challenges today, especially with regard to the role that Ultrasound technology plays in this issue. Even though Ultrasound scanners are proliferating and sex-ratios are falling, restrictions on import and manufacturing of the technology does not seem feasible, since Ultrasound technology is also used for other medical diagnosis.

The 2002 amendments made to the 1994 legislation make it more applicable and comprehensive. Thus more stringent legislation is not needed so much as full implementation of the existing legislation and amendment. The conviction of an Ultrasound practitioner in Haryana in March 2006 shows that under the law, those who allow and perform sex selection can be dealt with severely, as deserved.

Session 2, Presentation 2

Pre Genetic Diagnosis: Issues and Concerns

Presenter: Anita Ghai

Anita Ghai is a Reader in the Department of Psychology at the Jesus and Mary College, University of Delhi. A doctorate in psychology from the University of Delhi, she is engaged in interdisciplinary research on various facets of disability with a special emphasis on gender and education. She is the author of Dis (embodied Form): Issues of disabled women. Anita Ghai is a member of the editorial board of Disability and Society (Taylor and Francis) and Disability Studies Quarterly, published by the Society of Disability Studies.

Presentation

Preimplantation Genetic Diagnosis (PGD) is a genetic technology that allows for the evaluation of an embryo to determine if a disability is (or will be) present. In such cases, the parents can choose not to use the embryo, and thus they are selecting against a disability, raising issues of control, choice and selection. In the midst of debates about fertility and sex selection is a protest against the hegemony of the normal. Now there is a technology (PGD) that tells us we can produce what we'd like to produce, we can design without any discussion of what 'success' means in those terms, and without questioning what 'normal' means.

PGD can ascertain what the disorders are. So the choice is one of having a disabled child or not. But in terms of disability, where is the choice? Disability is defined purely in medical terms, but in fact it is a socially constructed definition. It depends on how I see disability. There was one instance where a deaf couple was going through IVF, and they requested a deaf child and people were shocked. Then there was another deaf couple that requested a hearing child – and all were relieved. Disability is caused not by the impairment, but by the society and by various environmental structures, not by the attitude of the disabled, but by the society's attitude.

There are typical arguments in the society either against having or to have disabled children, like, disability causes suffering, society is so unfriendly, why bring a disabled child into this life? Thus the use of genetic technologies becomes very attractive. Of the 25 narratives in a research study, almost half said they would abort the child or do whatever they could to avoid bringing a disabled child into the world.

If, however, a couple does choose to have a disabled child, insurance companies say: "Why did you decide to have a disabled child?" since a disabled child 'costs more'. And the blame for this almost always lands on the woman. To have a disabled child is almost as though you have committed a sin. But if it must be, it's best to have a disabled girl child rather than a boy, because the girl can be controlled/hidden more easily.

We have to question this idea of "quality of life". We have to ask, who decides on high quality? Who makes these decisions? And in comparing life with a disabled child to life with a 'normal' child, life with a disabled child is perceived to be difficult, but is that to say that life with a 'normal' child isn't difficult?

These kinds of debates about technology such as PGD and the decisions that can be made from it cause disabled adults to feel that the question is about their own right to live, that if the technology had existed decades earlier, perhaps they would have been aborted and their existence denied. And so, should there be a regulation that disallows abortion based on this technology? Who is to say that a different life is a life not worth living?

Comments and Questions from Participants:

- In sex selection, the XX chromosome becomes the disability factor. But with regard to physical disabilities, it's important to realise that about 95 per cent of disabilities are not congenital, so technologies like PGD actually only address about five per cent of disabilities.

- The demand and support for genetic screening comes from those who are sufferers of genetic problems. In California, a court has awarded damages to parents who had disabled children because their doctors did not do screening. This means screening will become routinised.

- The non-implementation of sex selection restriction is a civil society failure. This issue of supply and demand means it is a social demand. Why is it that one issue becomes the new 'fashionable' issue? We've known this rate has been a problem, but it's now suddenly an issue. Integrating the disability movement and the women's movement is vital. But each disabled individual is looking at his/her own needs, but the human rights needs are the same.

- Regarding the sex-ratio, why do we assume the ratio has to be 1:1? Is this is a State agenda? Is it really about sex selection? The State has really messed up with its various policies, (family planning, two-child families, female infanticide, etc). Maybe the various policies have resulted in the skewed sex-ratios from a history of failed policies. We are now addressing the embarrassment of the State's mistakes. Maybe we should rethink how to address this issue of worsening sex-ratio, maybe it's not just about sex selective abortions.

- There is a risk of oversimplification, saying only that the number of Ultrasound machines directly correlates to sex selection and abortions. Ultrasound machines are very useful and often save pregnant women's lives, as well.

- Despite the complexities and contradictions, the women's movement's stand on abortion is clear.

Comments from Presenters

- Vineeta: The women's movement has fought for the right to abortion and we don't want to let that go. That is why in the 80s, when sex selection was on the rise, the women's movement was paralysed between the two issues. It

was a real crisis. There is no doubt that we will have to redefine our position on selection. Also, it is necessary to clarify that Ultrasound is still a useful medical technology and we are not saying it should be banned.

- Anita: Why do we not allow selection as prevention? For example, if we can detect a breast cancer gene in a fetus – do we then select and abort the fetus?

Session 3:

Genetic Technologies and Research

Moderator: Sandhya Srinivasan

Introduction

In this session we will take a more in-depth look at some of the new genetic technologies that are being developed, the related controversies, both scientific and social, and some of the implications for the society and women.

Session 3, Presentation 1

Emerging Genetic Technologies and Research: The Inter linkages with Assisted Reproductive Technologies (ARTs)

Presenter: Sarah Sexton

Sarah Sexton works with the Corner House, a non-profit research and solidarity group which focuses on a wide range of environmental and social justice issues in the United Kingdom. In the past few years, she has written and edited several books and articles on various intersections between health, genetic and reproductive technologies, trade, population thinking, and issues of investment and refugees in the United Kingdom.

Presentation

The intersection between policies, practices, and health care comes naturally here in India. This presentation will explore the interlinkages between genetic technologies that are used for research and those used in reproductive technologies and examine what does this has to do with India, as well as the international level.

Dolly the sheep was cloned 10 years ago, but the researchers didn't even know why she was 'created'. They tried using an adult cell instead of an embryonic cell and it 'accidentally' resulted in Dolly. The scientists were thrilled. But the reaction in society was one of outrage as there was a fear that this can be done on humans.

But with cloning also came the discovery of stem cells, the embryonic cells that grow into all the various types of body tissues. There, a potential application was found

regarding whether stem cells can be turned into the type of cells in someone's body when their original cells aren't working? Such cells could thus have the potential to repair a damaged pancreas, heart, nerves, etc. This, then is 'regenerative' technology – using genetic technology for regeneration, not for reproduction. But where do regenerative and reproductive technologies intersect?

Researchers need human embryos to do stem cell regenerative technology research. At the same time, human embryos are formed during the IVF procedure. In addition, researchers need human ova, and when women go through IVF they produce 'extra' ova. This also raises the prospect of women providing their ova for research alone, as well, not just to donate for an IVF procedure. Thus, there are areas of overlap between genetic technology utilised for regeneration and for reproduction, and this is where the controversies and uncertainties lie.

In particular, there are vital questions about how researchers obtain embryos and eggs from women, such as:

- Should women undergoing IVF also be a source of embryos or eggs for research?
- Should unused embryos from IVF procedures be used for research?
- Can women who donate ova for IVF also donate for stem cell research?
- What are the ethics of paying women to donate ova for research?

While in some cases IVF may be a logical source of 'extra' ova or embryos, the ova that researchers would really like are those of younger women, not the older women seeking IVF. This means there is more demand for young women to be paid to donate their ova. In the above situations, issues of consent and 'ownership' become paramount as well.

The range of reactions and policies to the issue of women giving ova for research varies widely from country to country:

- In Eastern Europe, the ova trade is strong. Activists are concerned about the consequences of women providing their ova for research, yet are wary of speaking up too much against it out of fear that the backlash would result in reducing women's access to IVF.
- In the UK we've argued that ova should not be taken from women not undergoing IVF themselves because of health risks.
- In the US, many activists feel that since ova 'donation' for IVF and/or research is already legal, more energy needs to go into making sure that there

are safeguards in place to inform women, minimise risks and prevent commercialisation.

What is the situation in India?

Stem cell research may be the next big boom after the software industry. The UK and India are working towards exchanging information and funding in the area of embryonic research, and India is seen as an excellent place to conduct pharmaceutical and biological trials. The Indian Government has been actively encouraging and supporting such research as well as genetic research for economic reasons. This means that the ova business will undoubtedly grow rapidly as well. In other words, research is being driven by economic factors, not by health or social factors. Thus, all countries need an 'India policy', especially regarding pharmaceutical research and medical trials outsourced to India. One particular area of growth is medical tourism. This includes people coming to India for sex selection, surrogacy and to buy ova.

There are five major areas related to these issues that demand attention in terms of how they impact women:

1. Issues of choice, autonomy, control of one's body, consent

In some places these concepts have been used by women to obtain some measure of decision-making regarding their fertility. Now these concepts are being manipulated to justify some of this research. "If a woman consents, what's the problem?" The concept of 'choice' can also be misleading since it applies to those who have options, but in many cases women may feel they have little or no choice due to economic pressures. This is the case when women are providing ova because of financial needs.

2. Alternatives as a way to solve the problem

"Finding alternative methods" is often proposed as a solution to problems, meaning "alternative ways to obtain women's ova, alternative sources of embryos", etc. Some of these alternatives under research are:

- Taking a slice from an adult woman's ovary and researching how to get the cells to release the ova in the laboratory.
- Taking ovaries from female fetuses aborted at a late stage and finding ways to mature their eggs in the laboratory.
- Genetically engineered fetuses so that girls are born with their full 7 million complement of eggs.
- Creating eggs by getting human embryonic stem cells extracted from spare IVF embryos to develop into egg cells.

3. Health for whom?

Stem cell research is not about health for all. The discussions of how these technologies can be applied do not address who would have access to or would benefit from genetic technology-based treatments. In a privatised system, only those who have money will be able to afford such treatments. This kind of research also continues to divert funding, including public funding, from other avenues.

4. Alliances and alignments

This issue of stem cell research is controversial because it involves embryos, and so is opposed by those who oppose abortion. Thus through this controversy, opposing groups such as progressive women's groups and anti-abortion groups can appear to be linked. It is very important to be aware of this tendency, since incorrect conclusions about ideology can easily be drawn.

It is important that internationally, groups work together without undermining each other domestically and without imposing their own values and agendas on each other.

The international implications of bans and regulation is critical to keep in mind. Banning a procedure in the UK could result in researchers moving their work to another, more easily exploited country, recruit 'donors' from elsewhere, or cause standards to be lowered in other, poorer countries.

5. Is cloning only a diversion from where our energies should really go?

Other researches are underway in the genetic field, such as drugs and testing, DNA databases (crime, tracking, etc), screening technologies like PGD, etc. Should we focus more on the companies and those who support them financially and which exploit women? For example, while IVF does not affect everyone, PGD affects everyone and influences the perception of the disabled. Where do you draw the line, who's drawing it and why?

Research in Genetic Technologies: Reality, Hype and Concerns

Presenter: Satyajit Rath

Satyajit Rath is trained in medicine and works as an immunology researcher. He is associated with the Coalition for Nuclear Disarmament Peace, and is also a member of Delhi Science Forum.

Presentation

To start with, there are some more areas with respect to PGD itself that we need to look into. There are issues that need to be decided by civil society and not by the government.

1. What constitutes disease, and what kind of action do we accept being taken?

2. How do we distinguish between disease and risk? (such as the breast cancer or colon cancer markers that indicate a higher risk for the disease, etc). In the past, the requirement was that we must be able to pinpoint the source of a disease before we treat it. Over time, this demand has been diluted until we are at the point where we are treating risk as a disease itself.

However, this presentation will focus on technologies not yet talked about that are likely to appear in the future. There is a tendency to treat technology as magic, and if we understand it too well then we feel we won't be able to blindly trust it. Along these lines, the distinction between human cloning that would make a whole person versus making embryonic stem cells must be made clear for civil society. Otherwise the magic, science fiction-style implications can be a distraction.

New technologies

1. Somatic Stem Cell Research

In response to the fact that stem cell work is seen in a negative light and is difficult, one response has been to work on Somatic stem cells instead. In every organ of the adult body there are cells that are not completely formed into that organ's tissue. Less mature cells in the tissue can thus be coaxed to undergo proliferation and differentiation. Nerve, bone marrow, heart, brain, muscle cells can be

manipulated/transformed in this way. These somatic stem cells can then be reimplanted into the ill organ and this seems like a 'reasonable' alternative that does not involve the use of embryonic stem cells.

However, there is one concern regarding the somatic stem cells. You can't implant somatic stem cells from one person to another because of immunological limitations. In addition, it is a painful and difficult process and there are many obstacles. So how can this be solved? Take the somatic stem cell from someone else, take the nucleus from that cell, replace it with the nucleus of the target person, and then grow the stem cell into cells which will then have the immune properties of the target person. This is not yet being done successfully, but is being worked on.

Now, this again has the same problem as we have been discussing. It may not be a gender concern at this point of time, but it means that some sections of the population could be coerced into being sources for the original stem cell.

2. Genetic Engineering

All the technologies discussed thus far involve complete and whole DNA in a cell. None of these involve genetic engineering, which is where we talk about selectively clipping segments of DNA. The idea of "designer babies" is genetic engineering, where genes with undesirable traits are changed or exchanged with other genes that have desirable traits in order to control the expressed phenotypes. This can be done by either controlling the activity of genes, or, by making an inactive gene functional and with new scientific developments this is currently possible.

The problem is that all genes originally have a particular position in the DNA chain. If you want to 'put back' a modified segment there are two ways to do it.

The first way is to put the modified segment near the chain, so that that segment replaces that part of the chain exactly in the correct place. This "targeted replacement" is very sophisticated and very unsuccessful.

The second way to introduce a gene into the sequence is to 'hammer' it in, and it gets in there somehow, along with the controllers to trigger the gene, etc.

But in a clinical trial in France, problems are arising out of just such a procedure. Children with severe immune deficiency were 'corrected' by taking stem cells from their bone marrow, inserting a working copy of the gene they lacked, and replacing it into the their bone marrow. It was felt that they should then be able to make an immune system where they had none before. Eleven children were given this treatment in France.

After this procedure, all showed an appearance of a near-normal immune system, seemingly a 'successful' treatment. But, then slowly one by one they began to develop leukemia and at this point there are now around four of these children that have

leukemia. This is because when you put the gene in randomly, in each cell the gene is going into a different site, and so each cell is likely to have differences in its chain order. Blood cells are being made all the time and so if even one cell had enough DNA changed by the random insertion to convert the cell into an uncontrolled cell, this can result into developing leukemia.

Random insertion is always going to have these kinds of problems. And thus, this is where civil society will have a say in what's permissible and what's not.

Session 3, Presentation 3

New Developments: The Road Ahead

Presenter: Prabir Purkayastha

Prabir Purkayastha represents the Delhi Science Forum. He is a practicing engineer with an interest in issues related to Science and Technology, Policy and interface areas between Science and Society.

Presentation

Science and technology have reached levels where we can change nature and even create our own nature. 'Designer babies' mean both creating things and destroying. Science is seen with much more skepticism and fear, as in 'knowing too much'. And so we must look at the relationships between science, technology and society as these new and sometimes frightening technologies with heavy social implications, are being developed. It will help to take a look at the structure of scientific development and its ethical and philosophical underpinnings.

When we have advances in science, we increase both possibilities of both creation and destruction.

The great advances in science are not always accompanied with great advances in technology, and vice versa (i.e., technological applications of relativity versus semi-conductors). So it is possible that breakthroughs in the genome or in genetic science may not result in great applications in technology. We can't tell in advance which discoveries will result in new technologies.

And even experiments, the science itself, can be dangerous and have risks. How do we evaluate risks regarding science and technology? What is acceptable or not?

If scientists are going to conduct dangerous experiments or are demanding public money for experimentation, then the society must have a say in deciding what is acceptable. When the scientific community is complicit in the profit-making industry, this must be regulated because the scientist is no longer neutral.

Science and technology need regulation and boundaries, and many of these technologies should be looked as ethical issues by society. Cloning is not an issue of science; it is an issue of the society.

Regarding the risk evaluation, science needs to be demystified and then one can decide how to determine the risk. But risk analysis can be very confusing. Taking the extremes of complete safety or complete danger is not useful or possible. Using the precautionary principle to an extreme, claming that there will be no risk or no danger, is not possible. 'No risk' cannot be proven. Risk is made up of the probability of an event and the impact of an event. Thus, the scientist's responsibility is to state the risks, and then decisions must be made by the society.

These genetic technologies are highly inefficient, and the level of competence of Indian scientists within India itself is questionable. These factors also need to be taken into account when assessing these areas of genetic research and technology.

Session 3: Discussion

Comments from Participants

- Isn't the distinction between the scientific community and the civil society being made too easily? Isn't that too simplistic or naïve an approach?

- There is no framework for regulations (i.e. between science and the society); can we set criteria about what is acceptable according to a society?

- We say we cannot predict what will happen with new scientific developments. Though scientists can tell the risk involved, the decisions about what should be done should be left to civil society. But I don't know who this 'society' is, because they are often the same people making the other decisions.

- Are we really looking at the emancipatory potential of research? In this case it's mostly women. Shouldn't we be concerned about the impact it's having on the researched?

Responses from Presenters

Sarah: The issue of regulation is a thread in most of these discussions. This is the very point of the linkage between national and international development. This is why we

need to share and strategise without undermining each other. In the UK, there is a course that teaches radio communication skills to stem cell researchers so they can communicate with the public in a particular way. The UK government funds this course! This is why it is a very unclear issue, the issue of who is making decisions? Who is really regulating? Is it the financial market or the international trade agreements? Basically any regulation that impedes profit making can be challenged.

The risk of critiquing 'choice' and 'consent' is very high. I think this group can be sympathetic to the fact that those concepts can be used for goals and intentions that we perhaps do not want to go along with.

Satyajit: Regarding the proliferation of these technologies and actual competence in India, these are multi-layered processes and thus the inefficiencies are hidden. International researchers say they are doing stem cell research as basic research – but it doesn't make sense because if that was true, it wouldn't need to be done on/with humans.

Someone develops a technology for future profit but then calls it 'science'. In India, those who are supposed to be engaged in scientific developments in order to understand the world around us say they haven't succeeded very much because they have been busy developing technology 'in order to improve the lives of the teeming millions of India.'

Prabir: It is not to say that the science-society relationship is easy. But the scientists cannot make these decisions alone. We can't be completely libertarian, and we can't stop all science either. The question is how to set up structures that allow this exchange between the society and science and how to regulate this.

Profit is the dominant motive in such circumstances. In lieu of all this, it's now time to regulate scientific research, and this regulation is important even with the de-corporatisation of science.

Film Screening: The Price of Eggs

Following the day's presentations, the participants viewed The Price of Eggs, a BBC documentary about the ova donation industry for IVF 'treatment' in the United States. The documentary was illuminating as it revealed some of the rhetoric and justifications proffered by women donating ova, and demonstrated the deep societal lack of understanding of genetics as evidenced by the process of choosing donor criteria based on many non-genetic characteristics. Recipients asked for donors with particular SAT scores, with particular personalities or with particular hobbies and skills, somehow assuming that these were genetically transferred traits.

The donor agencies had highly developed marketing techniques, offering donors who were perceived to have the most socially desirable traits, apparently accepting only very attractive, slim young women. These choices, and deselecting a larger variety of women (considered 'undesirable'), were evidence of thinly disguised 'positive' eugenics. In addition, the doctor's attitude towards the women clearly showed the risks and results of commodification of women's bodies, particularly when a doctor referred to one woman as being 'a good hen'.

Day 2

Presentation of Discussions of Day 1

Presenters: Deepa Venkatachalam, Saswati Bhattacharya

Presentation

The themes and threads that emerged from the discussions of the first day were compiled and reviewed and a brief overview of the highlights of previous days discussion is as follows:

- Conceptual linkages between contraceptives ARTs
- Do these technologies have the potential of subversion?
- Kinds of 'infertility' treatments
- Revisiting of language and categories – 'infertile', 'childlessness'
- Revisiting level strategy, specifically ban on certain technologies
- Need to develop a language to debate and discuss – let us be cautious in using words like 'choice', 'agency', 'consent' and 'rights' when we take a position about NRGTs – strategise so that these words do not get co-opted by others
- Essentialism of motherhood and the social pressure/stigma
- Avoiding and using with caution certain essentialisms
- Is choice inherently bad, or should we have a space where there are various options, and non-negotiables are clearly defined?
- Political economy of 'infertility' – lack of data on the incidence of 'infertility' and the impact on growth of this industry
- Globalisation, over-medicalisation and reinforcing of patriarchal social values to control women's bodies
- ARTs as a growing market that operates within a profit paradigm

- Exploring adoption as a viable option. Under what circumstances do people choose to or not to adopt?

- Role of screening technologies, and the need to review /redefine the women's movement's position on screening – is screening for disability ok and sex selection not ok?

- What is 'disability'? How, when, and by whom does it get constructed?

- Genetic engineering and stem cell research – different contours of exploitation, not only of women but also of all individuals who are in marginalised positions.

- Developments in scientific research are often equated to developments in technology

- What is disease? Are we not treating risks as disease when we are talking of screening?

- Regulation – of techniques, of 'scientific' research – both at the national and international level. Regulations within a country is neither a sufficient or a necessary condition to stop certain practices

Session 4:

Eugenic Concerns

Moderator: Veena Shatrugna

Veena Shatrugna is the Deputy Director, National Institute of Nutrition, Hyderabad, and is one of the country's leading health activists. Her areas of work include nutritional concerns of women and children. She is one of the authors of the renowned health book in Telugu, Savaalaksha Sandehaalu: Streela Arogya Samasyalu (One Hundred Thoughts Doubts: Women's Health Problems), and Taking Charge of Our Bodies: A Health Handbook for Women.

Introduction

Many of the New Reproductive Technologies (NRTs) could easily be (and in some cases already are) being exploited in eugenic ways. The presentations in this session will explore some of the history of eugenics, revealing its ongoing covert and overt existence in society today, especially in connection with assisted reproduction.

Neo-Eugenics, Dysgenics and the Renaissance of Barbarism

Presenter: Mohan Rao

Mohan Rao is a public health specialist and teaches at the Center of Social Medicine and Community Health, Jawaharlal Nehru University. He has worked extensively on the history and politics of health and population issues in India. Mohan Rao has also edited a book Unheard Scream.

Presentation

This presentation will provide a history of eugenics and the Eugenics Movement in the West, and look at what we can learn from it.

Charles Darwin and the ideas of natural selection and survival of the fittest played a great role in the development and strengthening of the Eugenics Movement. These principles of selection, when applied to human population, were very appealing to those who considered themselves to be at the top of the evolutionary ladder, since it meant that they had 'won' the competitive struggle. This had frightening consequences and deep ethical and moral implications, as these 'founders' such as Darwin and his colleague A.R. Wallace, Darwin's cousin Francis Galton and others were identifying the 'best' qualities, or 'best' people in comparison to inferior groups. A small group of rich professional people thought they were in control of what they saw as the destiny of civilisation. They and others drew conclusions that in fact the numbers of the 'inferior' are always greater than the 'superior'. It was the 'lowest' types of people who were multiplying the fastest and thus were reducing the quality of humanity. In the 1800s there was a great wave of Racial Theories about the superiority of the White Race and coupled with the powers of colonialism eventually led to declarations of 'positive eugenics', that only the best and brightest should be encouraged to breed, and acts of 'negative eugenics' such as sterilisation, all in the name of reaching ideals of what they thought humankind can and should be. And it was not just science, it was a range of individuals and disciplines that propagated these ideas and it was the idea of the age.

Eugenics was supported by wide groups of people including the scientific community, politicians, etc., both in Europe and in America. Such groups initiated or condoned actions such as segregation of 'less desirable' members of the population, and ultimately culminated in the extreme acts of Adolf Hitler. And so eugenics was not discredited by science, it was discredited by Hitler.

What is seldom mentioned, however, is that Adolf Hitler's policies were not new or even his own; he found much support in the earlier American Eugenics movement, which had in the early 1900s supported breeding associations, and legislation restricting immigration of those not of 'white' stock, and using IQ tests to 'filter out' unwanted immigrants. There were also marriage laws controlling marriage of people with mental illness and disease— marriages were prohibited to the 'eugenically unfit'. There is a long history of a variety of similar legislation and eugenistic policies based on 'fitness' as well as Race.

This history carries over into today more subtly, with new genetic technologies such as raising issues of de-selection based on disability as well as choosing donor reproductive materials from 'ideal' human beings.

But this form of positive eugenics implies imposing genetic homogeneity, despite the vast genetic polymorphism of the human race. There is little information about the reliability, safety or even eugenistically positive outcomes of many of these technologies, which have also caused great ethical and moral debates. In addition, it completely ignores the role of environmental factors such as drugs, food additives, etc. which might account for 80 per cent of human mutation. This is a distortion of science, when a gene is considered a unit of evolution, when an individual is considered the unit of adaptation, and culture is seen to be genetically determined.

This age of the neo-liberal world has been called the "renaissance of barbarism", characterised by a lessening of the role of the State, huge increases in economic and social inequalities with increasing marginalisation of large sections of the population. Similarities have also been drawn between Malthusian times and the 1990s. Both periods were characterised by a relentless drive to create free markets, not spontaneously or naturally, but as a result of power and statecraft. In today's age, the result is a new global market largely unconstrained by public action, and this is being supported by the second wave of imperialist globalisation. Thus, imperialism and fundamentalism easily complement each other as larger identities are broken down and political forces feed on each other, and we see instances of 'racial cleansing' and ethnic nationalism. Thus the fear and anxiety about the future people feel make it easier for them to be complicit with morally offensive policies, such as perpetuation (or rejection) based on Race, despite the fact that we know now that biologically there is no such thing as Race.

The yearning for ethnic purity – or indeed purity of any kind – was what underlay the great eugenic experiments of the past. It is ironic indeed that today when we know that there is no such thing as Race, ideas of Race and purity have obtained a fresh lease on life along with new fears and new anxieties. The new genetics may well play along these fears and anxieties.

Eugenics of the Everyday: Some Preliminary Reflections

Presenter: Betsy Hartmann

Betsy Hartmann is the Director of the Population and Development Programme at Hampshire College in Amherst, Massachusetts, USA. She is also a member of the Advisory Committee of the Committee on Women, Population and Environment (CWPE). She has authored many books and articles including Reproductive Rights and Wrongs: The Global Politics of Population Control and The Truth about Fire, and the co-author of A Quiet Violence: View from Bangladesh Village. Her current work focuses critically on the nexus between population, environment and security. She is also the co-editor of an anthology titled, Making Threats: Bio Fears and Environmental Anxieties.

Presentation

This presentation will look at how eugenics permeates in everyday life. It is very important to look at eugenics in context, since eugenics is not a self-supporting field. It latches onto and feed off of other ideologies such as socialism, medicine, politics, biology, and can be used to support a wide range of movements in elusive and misleading ways. Thus, it seems that the challenge for progressives and feminists is not only to locate the 'purer' applications of eugenics, e.g., in genetic engineering directed at producing 'enhanced' human beings, but also in the intersections and convergences with other social, economic and political arenas. Our purpose here is to elucidate some intersections between eugenics and other biological deterministic practices.

There is a strong false narrative, that 'eugenics died in the USA with the Nazis' – but this is not true! Overt Racism became less acceptable, but within Races discussion continued about being genetically fit or unfit. But in reality the norms came from upper and middle class whites, and compulsory sterilisation policies continued into the 1980s.

In the realm of population studies, eugenics remained a powerful force, with great concerns over the population 'explosion' in the Third World, and determined who would be targeted for population control.

Eugenics also remained in the biological sciences, as the new field of molecular biology was used to support eugenics thinking as genetic control came to be seen as a way to purify the population.

Thus today we are not seeing so much a new resurgence of eugenics as new variations but with historical roots. Eugenics thought today now has intersections and convergences in a very wide range of fields. The power of eugenic ideology lies partly in its capacity to not draw attention to itself, to appear commonplace, which is why contextualisation is so important.

Environmentalism/Immigration

Early conservationists believed in preserving the 'pristine wilderness' or purity of both nature and the gene pool, and the manifest destiny of the White Race to both colonise and steward the environment. Immigrants were seen as a threat to this environmental purity – both the human and ecological environments. Fortunately, groups are beginning to expose these links, and calls have been made to remove population control from the environmentalist movement.

Gender, Sexualities, Bodies

There are now claims that especially in countries such as China and India, there are too many young, unmarried men and thus they pose a threat to the security of society. These young men are usually described as being poor, transient, aggressive and prone to violent crime, and substance abusers. This approach blames biology, both genetic and hormonal (single males) for behavior rather than addressing political or social factors that may be at the root of such problems. Biological determinism of this sort reinforces rigid gender definitions for both men and women.

Queer rights activists also have to deal with such issues in the search for a genetic basis for homosexuality. However, the search for a gay gene was instead seen as a strategy to win greater social acceptance and legal rights for homosexuals, since they could then not be discriminated against on the basis of their biology. But this is also dangerous, as it reinforces eugenic thinking in other arenas (Race, crime, etc.) and does not challenge homophobia.

Eugenics is insidiously found in human aesthetics, where promotion of ideal body types and the beautiful, efficient and controlled body has been present in racist research, contests and the media. Today, this takes the form of selection of women to be egg donors, the highest paid donors being blond, blue-eyed Ivy League women.

Race

Race continues to be a source for eugenics to manifest, such as claims that racial differences in disease are due to genetic differences. This oversimplifies the role of genes as causal agents and diverts attention from the social, economic and environmental determinants of disease.

Neo-liberalism

The shrinking of the Welfare State casts more and more people as drains on the economy and the State, including the poor, the elderly, people of colour, and people with disabilities. This results in policies such as population control measures aimed at poor women.

Consumer choice

The concept of individual choice is crucial to the promotion of New Reproductive Technologies and the link with 'positive' eugenics. This is intricately linked to marketing of 'ideal' consumer goods, faith in technology and belief in consumer rights as the foundation of free enterprise and democracy.

Globalisation

The ideologies and practices of global outsourcing with regard to genetic engineering, ARTs, stem cell research and cloning must be looked at closely as indicators of which country is 'out front' in the race on the technological frontier.

Efficiency

All of the above are linked to the greater focus on 'efficiency' as the acceleration of competition, information, etc. put more demands on the human body and political bodies to make more 'efficient' use of resources. Hence eugenics is linked to the mad drive for 'efficiency'. Genetic technology to prevent both physical and mental disease is seen as more 'efficient' than dealing with environmental and social causes.

The national security

The escalating role of prisons and the military expose the eugenic concerns of the disproportionate rates of poor people and people of colour being incarcerated, usually during their childbearing years, and also being sent to wars.

In order to learn some things from history, it is important to remember that it wasn't the horrors of Nazism that brought the era of compulsory sterilisation to a close in the USA, it was the political actions of feminists, civil rights and immigrant rights advocates.

We need to look critically at how eugenics thinking penetrates and permeates a wide array of social, economic, political and scientific arenas.

In terms of genetic research and the New Reproductive Technologies, we have to become literate in both their science and political economy in order to make informed feminist judgments about what we are for and what we are against.

We need to use our political imaginations to create a more powerful vision of a non-eugenic future that celebrates diversity, creativity and difference, challenges neoliberal notions of efficiency and the National Security State, harnesses scientific research for the real benefit of humanity and the environment and does away once and for all with the false and dangerous categories of fit and unfit.

Session 4: Discussion

Comments from the Moderator

What is happening in India in the area of eugenics? State-supported and initiated policies seem to have eugenics built in (any state policy that interferes in private life has eugenics built into it). We must be wary of eugenics practices right under our noses that we don't see. Caste distinctions, the kinds of friends we have. These are everyday practices that we need to be wary of. What is the role of the private sector? It believes in profit. But, the private sector also sometimes plays the role of an equaliser by acting with the goal of profit, since they want to access all markets. For example, they utilise models from black community in order to reach the market, and this then helps equalise representation of blacks. The private sector plays a different role than the State and we need to look at that.

Questions and Responses

Q: One gets the impression that the debate on population control is no longer part of the North feminist movement and is more related to eugenics in the way you described. Is that something that's happening? In North feminist circles when I bring up population control, I get a reaction like, "Is that still a problem?" Maybe we should look at the emphasis on reproductive rights, etc., concerns that still exist in the South, maybe these are being pushed away.

Response:

Betsy: Within the American reproductive rights movement, there has been more influence by women of colour and reproductive justice, including population controls. But that's not mainstream. In our centre we try to keep population control in the forefront. We need to do more work in the schools. The neo-Malthusian mindset is still very powerful in the USA and supports prejudices, etc.

Q: The gay stance of: "I was born this way," is extremely commonly stated. It might be good to find ways in which biological determinism can be explored

and use its political potential without giving in to oversimplification or naturalisation of ontogeny. One way forward may be that this gives way for strategic essentialism.

Response:

Betsy: In general, genetics and environment both play a role. It's the interaction between them. Strategic essentialism may work for a while, but it may often play into other mobilisations, and so I am skeptical. Much race-based politics is strategically essentialist.

We need to find new terms and new language and turn things on their head and shake things up. There may be strange political bedfellows, but these do not need to become strategic alliances. We need new ways to put forward these ideas. How can we put out language that other people can understand? How do we make it popularly accessible?

We need to bring back the understanding of political economy into the movement.

Q: The idea of the 'pristine' can be worked up even further. "Matter out of place", fear of contamination. This can be used to operationalise the critique. The notion of contamination can be used to explore more deeply the patriarch and then begin to use that to mobilise politically.

With genetics, the metaphorical vision of the body has changed. Until now the metaphor was one of dangers to the body coming from outside and the need to protect the body from invaders. Not with genetics and screening, it's becoming the'enemy from within'.

Response:

Mohan: I feel a bit uncomfortable using this metaphor of contamination to subvert anything. These are more than metaphors. It is a brutal reality and should be addressed itself since it is a problem, not just as a metaphor.

Comments from Participants

- The history and influence of eugenics are closely related to the theories used to justify imperialism. There are links across so many disciplines, but in the women's movement a position is sometimes advanced that there are ideological concerns. There is at times in the feminist movement a tendency to pose or analyse issues outside of an ideological framework. If you look at the middle class in India, there is a eugenics kind of understanding, 'everyday' eugenics, and yet there is no questioning of it except within certain known circles.

- Hitler was a great proponent of non-smoking, vegetarianism, exercise, holistic medicine and homeopathy, and forefront in the fight against cancer. He equated cancer being a disease of the body with the Jews being a cancer to the people. There are many such metaphorical and real connections between the body of the person and the body of the society, such as what happens to incarcerated pregnant women, where if a pregnant incarcerated woman keeps her child she stays in jail, but if she gives it up to the State and agrees to go on Norplant, she is released on parole.

- We need to look at Ayurveda and the roots of eugenics in Indian society. The caste system is the head of eugenics. In Ayurveda, there is a whole chapter entitled 'eugenics'. We need to see how this section looks at woman's body, and the gender of the fetus. There is also a philosophy that the sex of your offspring is affected by your karma, because it affects which aspect of your atma materialises. The textbook of Ayurveda that promotes these ideas is being used now.

Session 5:

Economic and Commercial Concerns

Moderator: S (Chinu) Srinivasan

Chinu Srinivasan is the managing trustee of the LOCOST(Low Cost Standard Therapeutics), Baroda. LOCOST manufactures drugs that have been successful in demystifying the production process and demonstrate that drugs can be manufactured and sold well below current market prices.

Chinu Srinivasan has been involved in the movement on rational therapeutics and has consistently led advocacy on pro-people drug policy reforms.

Introduction

These presentations will look at the state of some of the economics of these new technologies and some other issues in the medical/ health industry in India, with an eye to the future, what is coming and what we need to be ready for.

Presentation 1

A New Climate for Marketing of NRTs, and Implications for Regulatory Processes

Presenter: Shree Mulay

Shree Mulay is a Professor with the Department of Medicine, McGill University in Montreal, Canada. She is currently the Director of the McGill Centre for Research and Teaching on Women, and the Assistant Director for the Endocrinology and Clinical Biochemistry Laboratories at the Royal Victoria Hospital.

Presentation

This presentation will cover:

- Medical tourism, GATS and WTO
- Factors that facilitate the growth

- Web pages on IVF and fertility clinics
- IVF providers' support and opposition to the ICMR guidelines
- Guiding principles of the Canadian Assisted Human Reproduction Act (AHRA) and Prohibitions

Two years ago, sixty women met in New York to discuss gender justice and the gene age. At that time, before the meeting I did a quick review of web pages for IVF clinics in India. Then, just before this Consultation I again did a quick review of web pages. And I found that since that time, in just two years, the number of IVF clinic web pages has quadrupled. This alone is a strong indication that we are now in an advanced level of this technology.

Besides NRGTs, another area of great industrial growth in India is the field of medical tourism. It is often stated that India has everything it needs to be very successful in medical tourism, such as qualified medical personnel, infrastructure and a large pool of nurses, since the West will need caretakers for their aging population. Medical services can be outsourced, similar to the call centers.

The Growth of Medical Tourism in India

India is becoming an increasingly attractive destination for medical tourism. There are a number of factors that contribute to the growth of this industry. As populations age in the West, more people need medical procedures, and the cost of medical care in the West is very high. India provides a low-cost alternative. In the past, Thailand was the most popular destination for medical tourism. But now India is competing strongly and beginning to take some of that market, since fees for procedures in India are from half to one fourth of the fees in Thailand. For example, open-heart surgery in Thailand is for $14,250, while in India the same procedure is for $4,400.

Opportunities for joint ventures with foreign partners for investments in hospitals in India have resulted in a growth in medical facilities. In addition, various areas or cities in India are becoming known for their specialisation in areas of medical tourism, such as New Delhi for cardiovascular treatments, Chennai for vision treatments, Kerala for Ayurveda, etc. India also offers a wide range of procedures, including some other popular medical tourism services such as kidney transplant, cosmetic surgery, Ayurvedic treatments - and ARTs.

Marketing and Development of ARTs in India

In looking at a selection of web pages on the internet advertising ARTs in India, there are many ART websites which show high quality facilities and use heavy Western-style marketing techniques to attract a Western audience. However, the quality and

clarity of information given on these websites was rated to be quite low. In addition, websites from hospital clinics were more likely to have more thorough and clear information than non-hospital clinic websites.

IVF clinics are proliferating because of the growing market and also because of the relatively low cost of setting up an IVF clinic. To set up a fully equipped ART center will cost about Rs 20 lakhs in a rural area and Rs 40-50 lakhs in cities.

There is little regulation of such clinics, and in order to raise the standards of the industry, certification of IVF clinics is being desired by some. A consortium of 43 IVF clinics requested that certification of IVF clinics be included in the ICMR guidelines.

How to Regulate IVF Clinics

The guidelines from the Canadian Assisted Human Reproduction Act (AHRA) include important parameters for ART regulation. They are useful to look at as another model of how ARTs can be regulated, and perhaps India can gather some ideas from these guidelines. Included in the Canadian guidelines are unambiguous statements such as:

- the health and well-being of children born through ARTs must be given priority when making decisions about ARTs,
- the health and well-being of women must be protected,
- trade in reproductive capabilities raises ethical concerns that justify their prohibition,
- there can be no discrimination in the use of ARTs on the basis of sexual orientation or marital status, and
- the importance of free and informed consent

Besides strong statements guiding the use of ARTs, there is also a list of Prohibited Activities in the Canadian guidelines. These are vital, and address several of the concerns about exploitation that have arisen today at this workshop. Everything below is declared prohibited in Canada:

- No creating human clones, and creating embryos for anything other than reproduction
- No transplanting non-human life into humans
- No compensation or advertisement for surrogacy or sperm or ova

- No creation of embryos without written consent of donors
- No sperm or ova donated from those under 18 years old

Related to the IVF industry, stem cell research is another threat to women. The creation of embryos under the guise of or for stem cell research can result in many ethical and exploitative dilemmas, and thus regulations are necessary.

Participation by civil society in determining the research agenda and setting priorities is the only way to ensure a rational health policy that balances the needs of primary and secondary health care with that of tertiary health care. It is equally important that in India, where there is a critical mass of scientists with social commitment and infrastructure for research, a research programme that addresses diseases of the poor be developed. People must not let multinational corporations set the agenda. India must develop its own indigenous technology and put biotechnology to use, if and when it is needed, for the benefit of the people.

Session 5, Presentation 2

Economic and Commercial Aspects of NRGTs: "Babies for Profit"

Presenter: Amit Sen Gupta

Amit Sen Gupta is associated with the Delhi Science Forum, a public interest organisation working on science and technology policy issues. He is trained in medicine, and works on issues related to public health, pharmaceutical policy, Intellectual Property Rights and other science and technology issues. He has been the secretary of the All India People's Science Network and is member of the international secretariat of the World Social Forum. He is currently the Joint National Convenor of the Jan Swasthya Abhiyan.

Presentation

The development of genetic technology is occurring at an amazing pace. What is driving the rapid development of such technologies? Much can be attributed to perceptions in science. When there is a perception that science can change what we are, or control what we are, this kind of science is a nearly irresistible temptation – this is the lure of "Big" science, which is attractive both to the scientists and to the public who feel they will benefit. This perception of benefiting from such technologies is related to a shift towards genetic essentialism – the perception that our genes and DNA are the essence of who we are as human beings.

Private enterprise is largely driving the development of this 'new frontier'. Small-scale research is possible in this 'Big' science, unlike large projects in physics, etc. All that is needed are small labs. It is not difficult and not expensive (relative to other 'Big' sciences). In addition, patents are a ready source of revenue. And since there are more restrictions on public funds used for science than on private, privately funded research is more attractive.

However, such readily available technologies are tending towards a new eugenics, as the technology seems to make it possible to create the 'perfect' human being. Considerations of "Who is a good donor?" illustrate this trend, as criteria at donor agencies include the 'most desirable' body structure, weight, height, eye colour, psychological profile, complexion, education level, etc. These criteria and technologies tend to reinforce conditions of uniformity, and not just of appearance, but also of how to regulate the body, i.e., everyone should look perfect, all post-menopausal women should be on hormones, all adults should be on cholesterol-lowering drugs, all embryos should be modified.

The development and enterprise of ARTs is almost entirely in the private domain. The fertility industry is a multi-billion dollar industry and growing. In the USA in 1996, over $2.6 billion was spent on 'infertility' care.

But despite all the hype and development about genetic technologies, surprisingly very little has really come from such technologies. The three major applications have been the production of human insulin, monoclonal antibodies, and gene therapy (an immune system treatment in France that has also resulted in Leukemia). Such applications reach relatively few people.

And yet there is burgeoning investment in this field. Such investment is supported because of the shift in the bio-medical paradigm of health – that the fault lies in our body instead of coming from the environment, or bacteria, etc. There is a growing belief that medical care lies in genetic technologies, and is thus reversing the earlier belief in social and environmental determinants. At the same time, because of research investments, the boundaries between academia and the market are disappearing.

As such boundaries become blurred, we must take a close look at who sets the boundaries and what is happening now. Usually scientists set boundaries, and they do things because they like to, not with a grand design in mind. However, in this case, commercial/social/political interests are also determining the design. And the argument for such unbridled and unregulated research and potentially ethically questionable applications is that freedom of choice is supreme. However, we must realise that private acts do have social effects and it at least requires argument and dialogue as to why social consequences should not be a matter of social concern.

The fertility 'market' in India is no exception to this rapid growth. There is a potential Rs. 400 crore middle class market and Rs. 4000 crore market overall in this industry.

This 'market' will certainly grow as accessibility increases and technology is developed further. Potential ways that the market could expand is through the development of low-cost options, satellite centers and ova/sperm delivery services. And it is possible that public sector reimbursement will increase, providing insurance coverage and making the technology even more accessible to more people. Possibly the majority of people who go to these clinics go just because they want a baby. But that's going to change, because of the concerns we have seen.

Session 5: Discussion

Questions and Responses:

Q: The public sector has driven initial investment and then the private sector has picked up. How much private sector money is in this for IVF clinics?

Response:

Amit: Regarding how much is spent by the private sector, the only data I have is from the UK where for ARTs 20 per cent of funding is through NHS and 80 per cent from outside NHS. This area of genetic technology is one that attracts maximum funding both public and private, but private funding is outstripping public. I'm not saying there should not be funding. I am saying the funding that's coming in is for the wrong kind of research and for the wrong premise. There is no questioning of why or what the aim of this technology is. This is "the death of ideology". Issues and perceptions are not being talked about in a framework, everything is individualised.

Q: Are there any agencies providing insurance? When did they begin to get covered?

Response:

Shree: Apollo hospital did get payment from NHS. Which means medical tourism is drawing resources away from the public health sector.

Amit: There are two organisations in India that reimburse: ONGC, Indian Railways, and Government of India reimburses for primary 'infertility'.

Q: Did you come across any figures about what are the problems regarding malpractice, pharmaceutical company corruption, etc? What kinds of things can go wrong, what has been going wrong?

Response:

Shree: Regarding tracking things that go wrong, it is hard to find such data, and the clinics sometimes manipulate data such as claiming a chemical pregnancy (embryo) as a success, not the successful delivery of a baby.

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Comments from Participants

- It seems that we are aiming for perfection and trying to eliminate disability. It is very frightening that there is no sense of questioning in the larger circles regarding what we are aiming for. Even if we are aware of the fact that most disabilities are not genetic, there's still the overall perception that we're aiming for perfection.

- There is a challenge for us to generate new ways to think about ethical uses of reproductive technologies and a reconceptualising of motherhood. The media and film and TV industry are propagating the image that you are a woman only if you have a baby and nurse by yourself. If feminists could come up with better scripts and stories for soap operas, it would provide a visible and very accessible avenue for better representation of women.

- We need to work out the means to take these discussions further about strategies where we can encourage reflection on the part of people who go in for these choices.

- Regarding insurance in other countries, in Massachusetts, private insurance is required by State law to provide reimbursement for 'fertility treatments', so here there is a crossover between the State and the private companies.

- In Israel, 100 per cent public funding for IVF is provided just after six months of trying to get pregnant.

- In India, the medical sector is the fifth most privatised in the world. Globalisation has converted the world into the vagabonds and the tourists. Tourists go at will where they want, and you have the vagabonds who have been dispossessed, forced to move into ghettos. Medical tourism typifies what globalisation is doing to this world.

Session 6

Legal and Ethical Concerns

Moderator: Amar Jesani

Amar Jesani is coordinator of the Centre for Studies in Ethics and Rights, in Mumbai, India. He also coordinates a training programme in research ethics for HIV/AIDS researchers for a collaborative project of Samuha (Bangalore) and the University of California, San Francisco (USA). He is a member governing board of the Anusandhan Trust. In 1998-2000, he coordinated a national committee to formulate, for the first time in India, Ethical Guidelines for Social Science Research in Health. He is also one of the founders of the Forum for Medical Ethics Society and its journal, Indian Journal of Medical Ethics.

Introduction

This session will introduce the whole idea about strategies. Ethics and law are connected to the idea of doing something and changing a situation. Ethics, regulation and law are very closely related. When we speak about ethics, we speak about what is permitted and what is not, it is a science of determining right and wrong. Let's hope that we will speak more on the area of ethics which is multidisciplinary; it invites political scientists, sociologists, and economists to come together and look at an issue. Ultimately ethics is nothing but a science of determining what is right or wrong. Either we ban something because it should not be in the society, or it is decided that if it needs to be there then it needs to be regulated. One of the problems of regulations is who regulates the regulatory bodies. Ethics is the moral of the society, and the law is the instrument to bring change to that morality, whether it is effective or not.

Session 6, Presentation 1

Ethical Concerns and Critique of National Guidelines in the Context of ARTs

Presenter: N.B Sarojini

N.B Sarojini is with Sama-Resource Group for Women and Health. Sarojini has been working as a health activist in the field of women's health for the last 15 years and is actively involved with the women's movement. She has been involved in Shodhini, a national-level research network on traditional medicine and alternative health system for women and actively campaigned against two-child norm and injectable contraceptives. She has been closely associated with different progressive organisations and networks such as the Medico Friend Circle and the Jan Swasthya Abhiyan.

Presentation

The purpose of this presentation is to review the status of policy at the national level (Indian Council of Medical Research (ICMR) Guidelines, ART Regulation Bill) and develop a critique of the existing documents, incorporating ethics into the critique.

In 2000, ICMR released a document called "Ethical Guidelines for Biomedical Research on Human Subjects". This document contained a chapter suggesting guidelines for the practice of ARTs. Then in 2002, ICMR released another draft of guidelines specifically on "Accreditation, Supervision and Regulation on ART Clinics in India", and finally published it in 2005.

The ICMR's approach to ARTs is limited in terms of the social ethical aspects of the technology. Apart from being gendered and moralistic, the contents also glorify the technologies at various points. The guidelines are focused on the heterosexual and monogamous married couple, and leave out nearly all who do not fit this model.

1. Rationale for IVF in the guidelines:

The ICMR explicitly states its ideological basis behind the use of ARTs, specifically, that "IVF requires less surgical intervention than tubal canalisation", useful when a woman who has undergone a tubal sterilisation wants to again have children, often because of high infant and child mortality. Thus, the guidelines say that IVF is an alternative to the reversal of sterilisation, and so IVF is justified in view of family planning and also supporting population control.

The guidelines construct infertility as a 'disease' and the infertile as 'patients', that implies that medical intervention is the only way to deal with 'infertility'.

The guidelines state that "IVF is a therapeutic option of reproductive medicine with the highest yield per attempt, coming close on many occasions to that achieved by fertile couples conceiving naturally." The use of the word 'therapeutic' could be construed to mean 'curing a disease'. And the statement about the 'take-home baby rate', besides being of unclear basis, is very misleading since the real take-home baby rate is only between 20-30 per cent.

2. Language

Language is a central problem in the guidelines. The terms 'husband', 'wife', and in some places 'partner' are used. Lesbians, gays, single women and their concerns are not found in the text at all. The original draft guidelines in 2000 did have a mention of the issues related to gays and lesbians, but this too was somehow removed from the document.

"A child born through ART shall be presumed to be the legitimate child of the couple, born within wedlock, with the consent of both spouses and with all the attendant rights of parentage, support and inheritance." This emphasis on wedlock and legitimacy is problematic, since the implication is that only children born in wedlock are 'legitimate'.

The guidelines say that "ART used for a married woman with the consent of the husband does not amount to adultery on the part of the wife or the donor. AID without the husband's consent, can, however, be grounds for divorce or judicial separation." This reflects and reinforces the belief that a woman's reproductive role is totally in the control of the husband. The same act of insemination is interpreted differently depending on the husband's consent or otherwise.

3. National Advisory Committee (NAC)

There is a mention of the responsibilities and composition of the NAC and the State Appropriate Authority. However, the scope of these committees and how they would implement their powers is not brought up.

The concern is whether the accreditation process has commenced, then under which authorities are the clinics accredited? Hospital registrations or Medical Councils? And even if some clinics are registered, how would the public, the users, be aware of this and how can ICMR ensure that users go to authorised providers only?

4. Age

In the guidelines, ICMR points out that the "minimum age for ART for a woman is between 20-30 years, two years of cohabitation/marriage without use of a contraceptive, except in cases where the man is infertile or the woman cannot physiologically conceive. For a woman over 30, one year of cohabitation/marriage

without contraceptives. Normally, no ART procedure shall be used on a woman below 20 years old."

However, 19 providers surveyed said that women from age 18 years up to 55 years come to them for IVF treatments. Many said that women in their 40s and 50s would access treatment. In addition, this part of the guidelines reveals its inconsistency, here in regards to the maximum age, which at first is stated to be 30 years, but then a condition is given for women over 30 years.

There were also several mentions by providers of having treated menopausal women successfully. One provider questioned why ICMR should even be setting a maximum age. If a woman wants to get pregnant, why should ICMR tell her she's too old? While another provider said that the health risks for older women were prohibitive.

Regardless of the stance, the fact is that in the guidelines the maximum age is ambiguous.

Regarding surrogacy eligibility, the guidelines state that a surrogate mother should not be over 45 years of age and should belong to the same generation as the woman desiring the surrogate.

ICMR also maintains ambiguity in relation to 'age and eligibility' of egg donors and sperm donors. "Egg donors should be healthy in the age group 18 – 35" and then in another section it states that the age of the oocyte donor "must not be less than 21 or more than 35 years old".

5. Eligibility

Eligibility criteria set by ICMR for women desiring to use ARTs are essentially based on its own 'moral' standards. Though there is mention of single women in only one section, there is no reference to it in the consent forms. In addition, ICMR states:

"A child born to a single woman through AID would be deemed to be legitimate. However, AID should normally be performed only on a married woman and that too with the written consent of the husband as a two parent family would always be better for the child than a single parent one, and the child's interest must outweigh all other interests."

The guidelines also exclude gay couples, lesbians and HIV –positive women under the eligibility criteria.

6. Composition of the ART team

ICMR: "The practice of ART requires well-orchestrated team work between the gynaecologist, the andrologist and the clinical embryologist supported by a counselor and a programme coordinator/director."

In Sama's study of 25 clinics, only 15 had a gynaecologist and 13 had an embryologist. Only 3 clinics had an andrologist and 3 had a counselor. Most clinics do not have their own team but they have an arrangement with gynaecologists and andrologists. Most providers pointed to the added expense of full-time staff, and that counseling is done by the doctor him/herself.

7. Counseling

The ICMR Guidelines claim counseling to be a crucial component in the 'treatment ' process which would ensure that the users are thoroughly informed of the procedures and also consider other alternatives such as adoption before going for ARTs.

Research has revealed that little counseling is actually happening in the clinics, users are rarely well informed. In cases when a doctor is counseling, it is likely that alternatives such as adoption are not encouraged.

8. Informed consent forms

ICMR emphasises the need for informed consent, which must be obtained from the users of ARTs. A separate form for each procedure is included in the guidelines, as well as consent forms for donor sources, etc.

But there are many problems with language (i.e. husband, wife only), difficulty in accessing forms in local languages (they are easily available in English), insufficient information on the forms, and discrepancies with ground reality of providers limit the efficacy of these forms with the guidelines.

9. Sperm and Egg Donation

The guidelines say: "The use of sperm donated by a relative or a known friend of either the wife or the husband shall not be permitted. The same will be true for oocyte donation."

In addition, "neither the clinic nor the couple shall have the right to know the donor identity and address". How can ICMR monitor the whole process of sperm and egg donation? ICMR says that if semen banks are "set up by ART clinics, it must operate as a separate entity." It would, however, be very difficult to rule out covert dealings between the banks and the ART clinics.

10. Ethical and legal concerns

The cryopreservation of embryos is a tenuous and contentious issue. ICMR states, "Up to a maximum of three embryos are allowed for transfer...patients should be fully informed before the treatment on the procedure of cryopreservation, the risks and particularly, what is to be done with their embryos if they do not use them. They

should sign a consent form concerning the consent for embryo freezing as well as for the future use of embryos."

How is this process monitored, if the whole procedure is provider-controlled? And it is crucial to make clear what is to be done with such embryos in cases where embryos in cryopreservation are 'abandoned', or payment for storage left in arrears for whatever reason.

The guidelines state: "The sale or transfer of human embryos or any part thereof, or of gametes in any form and in any way, that is directly or indirectly, to any party outside the country must be prohibited. Within the country, such embryos or gametes could be made available to bonafide researcher only as a gift with both parties having no commercial transaction, interest or intent."

The concern is how ICMR can monitor and ensure that there is no commercial transaction taking place when there is such growing interest in embryonic stem cells.

Commercialisation of surrogacy is not addressed. The document says the ART clinics should not be involved in the monetary aspects. Regarding surrogacy, it also states: "A prospective surrogate mother must be tested for HIV and shown to be seronegative just before embryo transfer. She must also provide a written certificate that ...she and her husband have had no extramarital relationships in the last six months."

This impinges on the sexual life of a woman who would be a surrogate. And can single women not be surrogates? What about the sexual life of a single woman? How can ICMR assume that HIV can only be acquired only through extramarital affairs?

11. Sex selection through PGD

In the document, there is very little about sex selective abortions. But one demand from us should be audits of the hospitals/clinics. How many live births do they undertake with these technologies? This should be public information.

12. Providers' perception of the ICMR guidelines

Providers said they don't take ICMR guidelines seriously at all, since they are not legally binding, relevant or doable. Providers are unhappy about issues such as prohibiting unrelated donors, and the age criteria as set in the guidelines.

These guidelines have serious shortcomings in terms of narrow and exclusionary language, inadequate treatment of ethical issues, inconsistencies and ambiguities regarding criteria and a lack of strategies for monitoring and supervising clinics.

There is a new Bill (ART Regulation Bill) to be tabled in Parliament this monsoon session to provide for regulation and supervision of clinics, where to register them,

appropriate authorities, and penalties for non-compliance (but they are very minimal). Once we get copies of this Bill, then we need to review it and make sure we have a say and provide our critique. My concern is, when will we take up ARTs as a campaign issue.

Session 6, Presentation 2

Regulating Genetic Technologies for Women's Health

Presenter: Sangeeta Udgaonkar

Sangeeta Udgaonkar is an advocate specialising in intellectual property rights in Bangalore, Karnataka. She has been practicing law since 1986. Sangeeta is a member of the Expert Committee on Intellectual Property Rights, Karnataka Biodiversity Board and several Institutional Ethics Committees, and publishes widely in legal and ethical aspects of biotechnology patenting.

Presentation

The presentation looks at the legal aspects of various issues within the ICMR Guidelines, and how these impact the IVF clinics and their users. But before that I'd like to add onto some previous discussions based on the guidelines.

- in the guidelines it does say that a single woman can have a child, it is not clear about whether a single man can. While the guidelines will not change the law, it is probable that doctors will use the guidelines and incorrectly refer their patients in terms of the law due to inconsistencies.

- ICMR is binding on every doctor and the guidelines are operational and those not following the guidelines will be subject to consequences. They are enforceable by the Medical Council of India (MCI). And this is why they want to convert it to a Bill and put it in the hands of the police. If something is not done about these particular issues, there will be havoc for those doctors who want to do a good job.

With reference to this presentation the specific issues to be reviewed are

1. Oocyte donation
2. Surrogate motherhood
3. Genetic testing

4. Selection for a particular trait

5. Wrongful life (an issue that has not come up in India)

6. Adult genetic testing

7. Human cloning

Overview of the legal aspects of issues within the ICMR Guidelines:

1. Oocyte donation

Oocyte donation is highly invasive and cannot be compared to sperm donation in terms of risk. Once an embryo is made, the legal issue of 'ownership' and use of the embryo is ambiguous. The couple has no say when an embryo has been donated to a couple. If the receiving couple decides to give the embryo for research, the donor couple has no say in this. The 'ownership' of the embryo is transferred.

Payment for oocyte donation is only for purpose of ART. The payment is only to be done through law firms or sperm banks that then charge the couple. Such payment opens the door to exploitation, since 90 per cent of the time a voluntary donation will be for someone the donor knows, but the guidelines say that ova from a known person cannot be used. This will encourage paid donations of ova.

2. Surrogacy

There are two types of surrogacy, and each has its own legal issues. Gestational surrogacy is when the egg and sperm of another couple are implanted and the surrogate carries the child. Genetic surrogacy is when the surrogate woman donates the egg and carries the child.

Upon birth of the child, the right to the child is ambiguous. The law is uncertain and as yet there is no legal precedent in India. The ICMR code say the child belongs to the surrogate and the couple must adopt. At the same time, ART guidelines say the 'genetic' parents' names must be on the birth certificate and then the "genetic (biological) parents must adopt. This wording is conflicting and contradictory. The guidelines themselves are very contradictory, but the conflicting sections are in different sections and so it is not immediately clear upon reading the document.

The guidelines entitle the surrogate mother to monetary compensation. In surrogacy, the womb is not being transplanted like an organ, and so surrogacy doesn't fall under the restrictions placed on commercial dealings in human organs. The womb is being 'rented', not transplanted. Thus, payment for this 'service' can easily lead to exploitation of poor women. The guidelines limit the number of times a woman can be a surrogate, to a maximum of three– but do not take account of the number of

pregnancies a woman may have had prior to it. Surrogacy is however, allowed with known people and relatives, so voluntary donation is possible.

I feel that lawyers should not be involved in this process, however, according to the guidelines:

- A clinic can't advertise for a surrogate, but a law firm can (or sperm bank), and then charge the couple

- Law firms (or sperm banks) can pay for oocyte donation (and then charge the couple)

Yet these guidelines are for doctors, not couples, so how a doctor is supposed to make a couple work through a lawyer for these tasks is not clear at all.

There are other areas that are particularly sensitive legally, such as genetic testing. There are questions regarding the time of selection (pre-conception, pre-implantation, or post-implantation), the factor being selected for such as presence of particular 'disease' genes, which may indicate a likelihood of a disease, but not a guarantee, and the medical risks involved.

The legal ramifications of genetic technologies continue to be profound and as yet there are few precedents in India. In other countries, some landmark cases have identified legal criteria and definitions, but much remains to clarify the situation in India.

Session 6: Discussion

Comments from the Moderator

The issues of regulation deserve more focused discussion. What kind of regulation? Who will regulate? The State alone, or in cooperation with other stakeholders? Are we going to ask for regulation for every technology, every new thing, multiple laws, and multiple authorities? Or are we going to talk only about larger areas of regulations, like hospitals?

The whole idea of the law regulating certain things is of concern, and the mechanism for setting standards is changing as new things come up. Sometimes when a law is framed, it takes so long to make any changes to it. Can standards be set on a more frequent basis?

Regarding efforts to regulate hospitals, one must make an entity accept that regulations are needed, and then the regulation will be accepted. Can a strategy be developed for this?

Questions and Responses

Q: What about access for disabled women who want the IVF procedure, is there anything restrictive in the guidelines? In rural areas, mentally disabled girls are often used for their wombs, exploited.

Response:

Sarojini: Disability is not listed in the guidelines at all.

Q: It is surprising that surrogacy is being included in the guidelines, because the rest is about procedures. Should it be included in the Act at all? Keep the Act focused on the technology and procedures only. Other social implications have to be considered separately, such as who will be donors, whose child it is, etc.

Response:

Sarojini: The surrogacy consent form is included in the guidelines. And all the consent forms are only husband and wife, never 'partner'. In addition, surrogacy is included in the bill to be tabled.

Comments from Participants

- Surrogacy should be included in the guidelines. The sale of gametes should not be permitted, and the principle should be established that surrogacy should not be compensated except for expenses. If it is not included, then it is being given no social value and it becomes simply a commercial interaction and comes under a completely different set of guidelines.

- A participant who attended a meeting that formed the regulation shared that there were regional meetings while setting up the biomedical research guidelines. They were resistant to including contraceptives in that document, and thus too much is fragmented and disparate. In the ICMR document, initially the preamble was very strong about the need to regulate because of commercialisation, but it was overturned and later the preamble had to be removed. She also made the following observations:

This is the first time ICMR has been interested in putting down guidelines for a procedure instead of just research. When developing these guidelines, the ICMR had five regional meetings in 5-star hotels in cities, sponsored by the largest IVF clinics in the area. And thus there is every reason to doubt their intention.

We know that hardly anything has been filed by the MCI. If it is going to be tabled very shortly, we need to work on it. Also, the upper age limit for IVF has to be included because there have been cases where post-menopausal women have

successfully given birth, but then the father dies soon after and so this upper age limit should be included.

There needs to be an independent autonomous body. This is where perhaps Sama can look at different acts to be able to develop a strategy/model that addresses many perspectives. The Canadian model is good because it addresses many of the concerns that you raised about these guidelines, such as not being able to discriminate on the basis of marital status.

No single body has any idea what kind of research is going on in the country. There is a need for a national organisation for accountability and we should make this part of our campaign.

Session 7

Engagement and Concerns

Moderator: Sabala

Sabala is a feminist health activist. She has been involved in trainings on health issues and has also designed trainings on women centred health care. She is an active member of Forum for Women Health. One of the books that she has authored is Na Shariram Nadi.

Introduction

We are going to discuss the engagement of various movements with ARTs.

Session 7, Presentation 1

Public Health Concerns

Presenter: Mohan Rao

Presentation

In this presentation we will flag some issues and discuss further some public health concerns.

Public health is a discipline concerned primarily with the health of the population. The unit of study is a population, and in public health one tries to understand diseases in a population over time, the natural history of diseases in a community, and prioritise which diseases require intervention.

The view of public health has changed dramatically over time. When public health loses its population perspective, the underlying philosophy changes to methodological individualism. The whole can be understood as a sum of its parts, and that relationship is one-way. In addition, the shift has become one of neoclassical economics.

This all leads to changing notions of causality, towards more proximate rather than distance causes, multiple levels rather than single, and freezing time, no longer looking at changes over time.

Historically, the initial momentum for water supply/sanitation public health revolution came not out of care for the people, but from economic concerns, that the state could save money if people lived in cleaner conditions. Social epidemiology focused on water supply and sanitation. Under Chadwick, the model focused further on what is necessary and sufficient to avoid disease.

Other shifts that have occurred in public health beliefs and practices:

1. Now public health has become geneticised, with the underlying change in belief that diseases are caused by a single gene, forgetting that genetic diseases are caused by multiple genes acting in combination.

2. Cost-benefit analysis is invalid for health issues, because the inputs and outputs cannot be quantified. As a result, financial constraints determine public health priorities rather than epidemiological resources. This assumes that technology available is necessary, effective and safe.

4. Cost saving and life saving are equally measurable in monetary terms.

Diseases are seen in terms of discrete and unconnected interventions. This means dissecting diseases into parts and not looking at the larger picture that will inform causes. This reduces the interrelationships among factors.

India has the fifth lowest spending per capita on public health in the world. What are the implications of this? Basic things are not available in public health, but huge resources are going towards the private sector and needs that are minimal or not real or are luxuries. There are too many doctors, not enough nurses.

From a public health perspective, looking at a whole population and its need for health and disease-free existence, ARTs are not a very high priority considering the still high incidence of infant mortality, hunger, TB, etc.

There could be one institution at each State level for public implementation of IVF, but it is not a high priority for use of public funds.

The current interest in ARTs is an indication of the country's decreasing interest in public health standards. Public health has again become associated with small interventions such as water supply and sanitation; in the same way maternal health is seen as iron tablets and Tetanus injections. The public health standards have really deteriorated. On one hand, basic health needs cannot be met, and on the other hand we have ARTs. There is no balance in public health in the current context.

Session 7, Presentation 2:

The Sexuality Movement's Response

Presenter: Akshay Khanna

Akshay is a founder member of PRISM, a queer activist collective based in Delhi, which focuses on the intersections between sexuality and various axes of marginalisation. He is currently pursuing his PhD in Social Anthropology at the University of Edinburgh, focusing on the Queer movements in India, and also the emergence of 'sexuality' as a political object in various people's movements and civil society formations.

Presentation

This presentation is not a representation of the experiences of queer people with respect to ARTs. Discussions on the issues of ARTs or NRGTs have been very limited within queer movement. Through this presentation an effort will be made to look at various issues of gender and sexuality emerging from the advent of ARTs in particular.

The idea of not essentialising motherhood as what is 'natural' or normal is very pertinent when it comes to the queer movement. This is also the significant factor that provides certain intersection between women's movement and various strands of queer movement, where these concepts have been articulated. Therefore, the question is whether the women's movement should open its doors to the people who are transgender, but identify themselves with women's movement? Although, diversity between women with respect to castes, religion, language etc. have been dealt with, the women's movement has not addressed the issue of diversity based on sexual orientation. In acknowledging all these diversities, the stable category of woman is intact.

This category of 'real'/ 'natural' woman and its comparison with people not falling within this category (transsexuals) is articulated in terms of reproductive capacity. The centrality of reproductive roles in imagination of women is most obvious in various policies of the State. For example, the primary context in which the public health system addresses the concerns of women is in terms of reproductive roles. The National Health Policy has recognised this as a problem to be addressed. Therefore, the main context of interaction between the State and the 'body' is in terms of reproductive female body. The implications of this are not limited just to the relationship between the female body and the State, but the female body is held as proxy for the population at large.

The question that ARTs pose in this light is, what does the advent of these technologies would imply for the 'naturalness' of the category of women? A queer approach to ARTs then means challenging the distinction between the 'natural', and the socially and culturally constructed, because what is taken to be 'natural' or 'normal' is itself socially, culturally and politically constructed and negotiated. Since science in itself is a socially constructed process, then the scientific definitions of male and female must be seen in this light of science being a construction, with a specific process of knowledge production and mechanisms of regulation. Therefore, instead of looking at ARTs as interventions that reinstate 'normalcy' in a condition of 'abnormality', we should see how these technologies affect the construction of these ideas in the first place.

This gives a larger political framework to view these processes of creating the view of what is 'normal'. For example, the idea of heterosexuality is constantly and vigorously reinforced through various processes and institutions. People falling outside this matrix must suffer stigma and marginalisation. Falling out of this heterosexual matrix is what drives the attraction to ARTs, because of the stigma of being 'abnormal'. Thus, access to technology is made possible in order to reinstate one's position in the heterosexual matrix.

The idea of intersectionality and intersection with ARTs

Various institutions of heteronormativity such as family, medicine, law and others constitute each other and also get constructed in the process. The exclusion, suffering, marginalisation faced by queer people or people who are gender non-conforming, these are the same institutions through which there is suffering related to childlessness. The images of each identity also include sexual dimensions along with identities of caste, religion, gender, class etc., and they feed into each other.

In the context of ARTs, this also becomes important. The ICMR guidelines emphasise the right of the couple to know details about the donor before accepting the sperm. And therefore, ARTs, besides reinforcing the image of the 'normal', 'natural' heterosexual couple, also reinforce the ideas of caste, family, class, etc. It is not merely the ability of man/ woman or couple to reproduce, ARTs promise the reproduction of heteronormative baby of the appropriate caste, religion, class etc.

Deifying motherhood (through images of various goddesses) is very close to the idea of Bharat Mata, and this has to be traced within historical context. The ideal of middle class motherhood became the image for an entire culture and these images circulate in the mind of the public domain.

In 2002, the ICMR draft guidelines stated that ARTs cannot be denied to lesbian/gay couples. It also included a statement questioning how society will be able to absorb these 'alternative' parents. Still, the statement is put in terms of acceptance in the face

of abnormality. These sections have since been removed in the final version of guidelines.

The important aspect is therefore to understand how ART clinics respond as part of the society and how the consideration of queer sexuality in the guidelines is cut away from their desires, experiences and politics in India and articulation of the same.

Session 7: Discussion

Questions and Responses

Q: Do you see any parallels between the disabled and queer movement in terms of ARTs?

Response:

Akshay: They are from the same sets of political realities. They are similar processes through which there has been a medical articulation of the normal. There is significant intersection in this area.

Q: Since gay sex is criminalised in India, how are we to take the process towards queer parenthood seriously?

Response:

Akshay: What is criminalised is the act of gay sex, and so there's nothing that says gays can't be parents.

Comments from Participants

- Law often offers an opportunity for subversion in the gaps in the way laws are framed and not fully articulated. It gives room for mobilising. In my research, the providers said these needs are not a problem in India. This is a big area for research.

- Another area in the queer perspective is the whole questioning of family itself. It's not just the biomedical category of infertility. We're also allowing certain kinds of couples to have children, and the basic unit of society is this particular family. This is what needs to be questioned in so many ways and what ARTs are doing in this area. They are completely reinforcing this model of the family. And so there is a resistance from queers to these technologies completely.

- ARTs are a medical, technological answer to a social problem, and the social problem (infertility) is socially constructed. Is this going to be the only

definition of 'family'? This needs to be remembered when we articulate our campaign. If there are certain rights for certain people, then they must be for everybody.

- When we develop our strategies, let's destroy this concept of family, parent and child, lineage through blood. Let's start deconstructing.

Emerging Concerns and Future Strategies

Moderators: Aleyamma, Swatija, Prakasamma

Aleyamma Vijayan is the Director, Sakhi Resource Center, Thiruvananthapuram, Kerala, which works on issues of gender, population and human rights. She has been working with the fishing community for about 16 years and has been the Country Coordinator, Women in Fisheries Programme. She was also a part of the team effort to create a network of women's groups in Kerala called Kerala Women's Forum.

Swatija is a women's health activist working as a volunteer for last 30 years in women's movement, with a keen interest in science and technology. She has co authored various books, papers and other publications on issues related to fertility, contraceptives and population. Swatija is a part of Forum for Women's Health.

Prakasamma has a public health background and is engaged in training and research on public health, midwifery and women's health. She was a professor in epidemiology and reproductive health and founded the Academy for Nursing Studies- an organisation for study of public health concerns and gender issues.

In this final session, we will tie together the many vital issues that have arisen from a variety of perspectives. We will look at an overview of these issues, elaborate on some of them, and then begin to develop a framework and strategies for the future.

An overview of issues to be addressed

1. *The issue of 'infertility' and the health sector:*

- Why speak of high-technology fertility without first addressing the lack of basic facilities, for example TB services?
- What are the reasons for 'infertility'? How do early marriages play a role in secondary infertility and where does primary health care figure in?
- Moreover, how is infertility perceived as? Social and environmental causes or changes are not addressed. Instead, a technological solution is presented for an evidently social problem.
- In what way is medical tourism promoted for infertility 'treatment'?

- Is infertility a public health concern? In our discussions it has emerged that it is not public health priority. Then in what form should it be addressed.

- Politics of public-private partnerships in this field.

- The link between medical technocrats and insurance companies.

2. *The notion of motherhood:*

- What does it mean to be a mother? Carrying a baby for 9 months? Giving care? Nurturing? Men can also give care and nurturing. The whole idea of biological motherhood as the only definition has to be looked at again, more minutely and sensitively as a social construct.

3. *Genetic engineering*

- Genetic engineering, at one level, seeks to eliminate all that is genetically 'imperfect'. In the face of this, can we let genetic engineering proceed unregulated? It is important to look at this process critically.

- The arena of stem cell research, and the potential it has for exploitation, must also be analysed.

4. *Eugenic Concerns*

- In India class and caste creates family structure in very complex way. And family structure to an extent, works towards maintaining the purity of genes. The demand for specific traits in donors etc. is reflecting the prevalent genetic essentialism. This needs closer examination.

- The mindset of monoculture being imposed on nature is also being applied to human beings.

- Sex selection and screening technologies and the implicit eugenic tendencies.

- The construction of disability, and the bearing it has on ARTs, especially with respect to PGD.

5. *Regulation of medical technology*

- In the face of increasing technological development, there is a need for regulation. And yet, can law really take responsibility for social issues? We are going to be a minority voice in a majority that says they want ARTs without questioning.

- Prior to proposing any regulation, it is necessary to discuss and critique it.

- Who needs regulation and for whom? Who decides, who monitors, who is accountable? Can we regulate a globalised world anyway?

6. Revisiting the terminology currently in use — childless, infertile, patients, disease, treatment etc. Also issues of consent, control, agency and choice need to be revisited.

7. *Commercialisation of ARTs in particular, and medical services in general, which results in commodification of women and womanhood.*

- Production of life has become a commodity. One needs to revisit NRGTs from this context.

- Control of women's bodies, sexuality in the context of technological interventions needs to be looked at.

- The existence of profit/market driven society - and the view it takes of women's bodies.

What could be the strategies?

- Taking up ARTs and genetic technologies as campaign issues.

- Priorities with regard to public spending.

- Examining public private partnerships.

- Strengthening primary health. We need to get back to how to do this and work on allocation of budgets in our future strategies.

- Prioritising and deciding what kind of research we would like. For instance funds could be used to address difficult diseases, as over cloning.

- Rational use of technology - technology over time has been looked at as an easy fix to emerging problems replacing the much needed focus on prevention. We have to decide on what we see as acceptable use of technology.

- Need clarity and consensus on certain issues and procedures. There is a need to involve all stakeholders like government, doctors, and NGOs in monitoring and regulating. A complete dependence on the State for the above is not the answer.

- Existing laws, regulations, programmes and policies need to be crtically examined and debated for public opinion.

- It is also important to engage with service providers.
- There is a need to give out correct information about these technologies.
- Newspaper articles, popular television serials, soap opera scripts, legal issues, and use of other forms of mass media to spread the information so that people can make informed decisions.
- The movement itself is divided over the larger issues. The issue of older women and their rights to be a mother, the surrogacy issue, commercialisation of women's bodies. In this scenario it becomes important to understand the various standpoints of those within and arrive at some common non-negotiables.
- Along with all our other strategies we do need to look at and work on developing language and terminology. Within the various movements too there is a lack of clarity and consensus on the use of language.
- These discussions need to be carried forward in other groups both marginally involved and fully comitted.
- Taking forward the discourse, public debates and building consensus.

List of Participants

1. **Aarti Mundkur**
   Alternative Law Forum, No. 4
   Ground Floor, 3rd Cross,
   Vasanthnagar, Bangalore-560052
   Phone: 080- 2235 6845
   Fax: 080- 2237 0028
   Email: arti@altlawforum.org

2. **Abhijit Das Gupta**
   Centre for Health and Social
   Justice,C/o Dr A. Das, C-152,
   Golfview Apartments, Saket,
   New Delhi-110 017
   Phone: 011-2653 6041
   Email: abhijitdas@chsj.org

3. **Aditya Bharadwaj**
   School of Social & Political Studies,
   University of Edinburgh, Adam
   Ferguson Building, George Square,
   Edinburgh EH8 7LL
   Phone: 0131- 6513861
   Fax:0131 6503989
   Email: Adi.Bharadwaj@ed.ac.uk

4. **Akshay Khanna**
   182, Mandakini Enclave,
   New Delhi-110019
   Phone: 09899313891
   Email: S0454533@sms.edu.ac.uk

5. **Aleyamma Vijayan**
   Sakhi-Women's Resource Centre,
   T.C. 27/1872,Convent Road,
   Thiruvananthapuram-695035
   Kerala.
   Phone: 0471- 2462251
   Fax: 0471 2574939
   Email: sakhi@asianetindia.com

6. **Allison Lide**
   Email: allisonlide@yahoo.com

7. **Amar Jesani**
   Centre for Studies in Ethics and
   Rights (CSER), Candelar, 4th Floor,
   26, St. John Baptist Road, Bandra
   (W), Mumbai-400050
   Phone: 022- 2640 6703
   Fax: 022 2667 3156
   Email: amar.jesani@gmail.com

8. **Amit Sen Gupta**
   Delhi Science Forum
   D-158, Lower Ground Floor, Saket,
   New Delhi-110017
   Phone: 011- 2686 2716/ 2652 4342
   Email: ctddsf@vsnl.com

9. **Anita Ghai**
   J/12/68B, Rajouri Garden,
   New Delhi
   Phone: 98111 54957
   Email: anitaghai@vsnl.com

10. **Anu Gupta**
    Eklavya, 33,Saket Nagar, Dewas,
    Madhya Pradesh
    Phone: 07272- 223496
    Fax: 0727- 21998
    Email: eklavyad@sancharnet.in

11. **Anuj Kapilashrami**
    Sama- Resource Group for Women
    and Health, B- 45, 2nd floor, Main
    Road Shivalik, Malviya Nagar
    New Delhi- 110017
    Phone: 011- 65637632, 26692730
    Email:
    sama_womenshealth@vsnl.net
    sama.womenshealth@gmail.com

12. **Ashok Kumar Yadav**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

13. **Antony Kurian**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

14. **Beenu Rawat**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

15. **Betsy Hartmann**
Director, Population and Development Program
CLPP, Hampshire College,
Amherst, MA 01002
Phone: 413 559 6046
Fax: 413 559 5826
Email: ehSS@hampshire.edu

16. **Bhamini Mehta**
Lecturer, Dept. of HDFS Lecturer, Dept. of HDFS ,
Faculty of Home Science The Maharaja Sayajirao University of Baroda, Fatehgunj,
Vadodara - 390 002
Email:
minimehtain@rediffmail.com

17. **Bharti Roy Choudhury**
Action India, 5/27A & 5/24A, Jangpura B,
New Delhi-110014
Phone: 011- 2437 7470/ 7473
Email: actionindia@hotmail.com

18. **Chayanika**
Forum Against Oppression of Women (FAOW), 19, Bhatia Bhavan, Babrekar Marg,
Dadar (West),
Mumbai-400028
Phone: 022- 2401 0482
Email: chayshal@vsnl.com

19. **Chinu Srinivasan**
Low Cost Standard Therapeutics,
1st Floor, Premanad Shahitya,
Sabha Hall, Lakadipool,
PandiaBazaar, Vadodara- 390001
Phone: 079- 413319
Email: sahajbrc@icenet.co.in

20. **Deepa Gupta**
Navjyoti Development Society (NDS), C-38, Basti Vikas Kendra,
Behind Chawla Hotel, Okhala Phase- II, New Delhi-110020
Phone: 011- 2638 4187
Email: jsad@bol.net.in
navjyoti@bol.net.in

21. **Deepa Venkatachalam**
Sama- Resource Group for Women and Health,
B- 45, 2nd floor,
Main Road Shivalik,
Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

22. **Indu Agnihotri**
Centre for Women and
Development Studies (CWDS)
25, Bhai Vir Singh Marg,
Gol Market, New Delhi-110001
Phone: 011- 2336 5541/ 2334 5530
Email: indu@cwds.org

23. **Jamie Hartmann**
Hampshire College,
Amherst, MA 01002,
Phone: 413 559 6046
Fax: 413 559 5826
Email: ehSS@hampshire.edu

24. **Jayeeta**
Centre for Health and Social
Justice, C/o Dr A. Das, C –152,
Golfview Apartments, Saket,
New Delhi-110 017
Phone: 011-2653 6041
Email: chsj@chsj.org
jayeeta@chsj.org

25. **Kamayani Mahabal**
Center for Enquiry Into Health
and Allied Themes (CEHAT)
Survey No. 2804 & 2605,
Aaram Society Road, Vakola,
Mumbai-400055
Phone: 022- 2667 3571/ 3154
Fax: 022 2667 3156
Email: koolkamayani@gmail.com

26. **Laxmi Murthy**
Saheli Women Resource Centre
Shop No. 105-106, Under Defence
Colony Flyover Market,
New Delhi 110024
Phone: 011- 2461 6485
Email: l_murthy@yahoo.com

27. **Madhavi Kuckreja**
Vanangana, Purani Bazar,
Chitrakoot, Uttar Pradesh
Phone: 094151 04361
Email: vanangana@rediffmail.com

28. **Malini Ghose**
Nirantar, B-64, Sarvodaya Enclave,
New Delhi-110017
Phone: 011- 2696 6334
Fax: 011 2651 7726
Email: nirantar@vsnl.net

29. **Manisha Gupte**
Masum, 11, Archana,
163, Solapur Road, Hadapsar,
Pune- 411028 Maharashtra.
Phone: 020- 2699 5625/ 2687 5058
Fax: 020 26811749
Email: masum@vsnl.com

30. **Manjeer Mukherjee**
Sama- Resource Group for Women
and Health, B- 45, 2nd floor, Main
Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

31. **Mira Shiva**
A-60, Hauz Khas, New Delhi-14
Phone: 011- 5168 8154
Fax: 011 26562093
Email: mirashiva@yahoo.com

32. **Mohan Rao**
Centre for Social Medicine &
Community Health,
School of Social Sciences,
Jawaharlal Nehru University,
New Delhi-110067
Phone: 011- 2619 6630
Email: mohanrao@bol.net.in

33. **Navsharan Singh**
International Development
Research Center (IDRC)
208, Jorbagh, New Delhi-110003.
Phone: 011- 2461 9411
Fax: 011 2462 2707
Email: nsingh@idrc.org.in

34. **Nidhi Sobti**
Sama-Resource Group for Women and Health, G-19, 2nd Floor, Saket, New Delhi-110 017,
Phone: 5563 7632
Fax: 011 2656 2401
Email: sama_womenshealth@vsnl.net

35. **P. Phavalam**
Campaign Against Sex Selective Abortion (CASSA)
11, Kamala 2nd Street, Chokkikulam, Madurai-625002
Fax: 0452- 253 0486/ 252 4762
Email: sirdmdu@hotmail.com

36. **Philomena Vincent**
Aikya, 75/76, Off 41 Cross, 2nd Main, 8th Block, Jayanagar, Bangalore-560082
Phone: 080- 26635876/ 2843 3175
Email: philo_vincent@rediffmail.com

37. **Prabha Nagaraja**
Talking About Reproductive and Sexual Health Issues (TARSHI)
11, Mathura Road, 1st Floor, Jangpura-B, New Delhi-110014
Phone: 011- 2437 9070/1
Email: tarshi@vsnl.net

38. **Prabir Purkayastha**
Delhi Science Forum
D-158, Lower Ground Floor, D Block,Saket, New Delhi-110017
Phone: 9811142462
Email: prabirp@gmail.com

39. **M. Prakasamma**
Academy for Nursing Studies
F1, Shiridi Apartments, Somajiguda, Opposite Yasodhra Hospital, Hyderabad
Phone: 040 - 2341 2027/ 2337 5931
Fax: 040 6661 1635
Email: hyd2_dirans@sancharnet.in

40. **Preeti Nayak**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar New Delhi- 110017
Phone: 011- 65637632, 26692730
Email: sama_womenshealth@vsnl.net sama.womenshealth@gmail.com

41. **Rajashri Das Gupta**
218B, Lake Terrace Extension, Kolkata-700029
Phone: 033- 2466 1759/ 6060
Email: rajashri_dasgupta@yahoo.com

42. **Ranjan De**
Magic Lantern Foundation (MLF)
Basement, J-1881, Chittaranjan Park, New Delhi-110019
Phone: 011- 26273244
Fax: 4160 5239
Email: ednajnar@gmail.com

43. **Ravi Duggal**
6 Staff Quarters,
HM Public School,
Andheri (West), Mumbai-400058
Phone: 022- 26286865
Email: RDUGGAL@gmail.com

44. **Ravindra R. P.**
5B/706, Sunrise Society,
MHADA, Dindoshi,
Malad (East),
Mumbai-400 097
Phone: 09869087883
Email: rpravindra@rediffmail.com

45. **Roshmi Goswami**
Ford Foundation,
55, Lodhi Estate,
New Delhi-110003
Phone: 011- 2461 9441/ 2164 8401.
Fax: 011 2461 7738/ 2462 7147.
Email:R.Goswami@ford.org

46. **Roshni**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

47. **Rupsa Mallik**
Center for Health and Gender Equity (CHANGE)
6365,C6,Vasant Kunj,
New Delhi-110070.
Phone:09313309594
Email: rmallik@genderhealth.org

48. **Sabala**
Vasant View 'A' wing,
Flat 201, D'Monte Lane,
Malad (West), Mumbai
Phone: 022- 28886237
Email: Kranti@bom5.vsnl.net

49. **Sandhya Srinivasan**
8 Seadoll,
54, Chimbai Road, Bandra (West),
Mumbai-400050
Phone: 022- 2640 0607/
098204 10849
Email: sandhya@bom3.vsnl.net.in

50. **Sangeeta Udgaonkar**
Wadia Ghandy & Co. (Advocates & Solicitors), 9th Floor, Vayudooth Chambers, 15-16 Mahatma Gandhi Road, Bangalore- 560 001
Phone: 080-4123 3127/ 28
Fax: 080 4123 3129
Email:
sangeeta.udgaonkar@wadiaghandy.com

51. **Sanjib Mukherjee**
384, Sultan Alam Road,
Tollygunge, Kolkata-700033
Phone: 033- 2417 5338/ 098310 31015
Email: sanmukh@cal2.vsnl.net.in

52. **Sarah Sexton**
The Corner House, Station road,
Sturminister Newton DT10 1YJ,
United Kingdom
Phone: +44 1258 473795
Email: sarahsexton@gn.apc.org

53. **Sarojini N. B.**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

54. **Saswati Bhattacharya**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.com

55. **Satyajit Rath**
National Institute of Immunology (NII), Aruna Asif Ali Marg,
Near Jawaharlal Nehru University,
New Delhi-110067
Phone: 011- 2671 7121/ 7145
Email: satyajit@nii.res.in

56. **Shakti Kak**
All India Democratic Women's Association (AIDWA)
121, VP House, Rafi Marg,
New Delhi-110001
Phone: 011- 2371 0476
Email: shaktikak@gmail.com

57. **Shalini**
Lesbians and Bisexuals in Action (LABIA)
C/O Stree Sangam,
P. O. Box 16613
Mumbai-400 019
Phone: 022- 2401 0482
Email: chayshal@vsnl.com

58. **Shree Mulay**
3487 Peel Street,
2nd floor, Montreal,
QuebecH3A1W7, Canada
Phone: 514-398-391
Fax: 514-398-3986
Email: shree.mulay@mcgill.ca

59. **H. Sudarshan**
Vigilance Director,
Lokayukta-Karnataka,
Multistoried Building,
Dr. Ambedkar Veedhi,
Bangalore- 560001
Phone: 080- 22257487
Email: hsudarshan@vsnl.net
vgkk@vsnl.com

60. **Suchita Chakraborty**
Sama- Resource Group for Women and Health, B- 45, 2nd floor, Main Road Shivalik, Malviya Nagar
New Delhi- 110017
Phone: 011- 65637632, 26692730
Email:
sama_womenshealth@vsnl.net
sama.womenshealth@gmail.comet

61. **Swatija**
Forum Against Oppression of Women (FAOW)
29, Bhatia Bhawan, Babrekar Marg,
Dadar (West), Mumbai-400028
Phone: 022- 2401 0482
Email: swatija@gmail.com
swatijamanorama@yahoo.co.uk

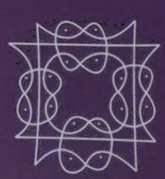
62. **Trupti Shah**
Sahiyar (Stree Sangathan),
37, Patrakar Colony, Tandalja road, Post- Akota,
Vadodara-390020 Gujarat
Phone: 0265- 251 3482/ 232 0399
Email: sahiyar@softhome.net
sahiyar1@yahoo.co.in

63. **Vandana Prasad**
L-91, Sector 25, Noida,
Uttar Pradesh-201301
Phone: 0120- 2253 6578
Email: chaukat@yahoo.com

64. **Veena Shatrugna**
Anveshi, OUB-1, Osmania University Campus, Hyderabad.
Andhra Pradesh-500007
Phone: 040- 2700 8921
Email: veena52@yahoo.com

65. **Vineeta Bal**
National Institute of Immunology (NII), Aruna Asif Ali Marg,
Near Jawaharlal Nehru University,
New Delhi-110067
Phone: 011- 2671 7121/ 7145
Email: vineetabal@yahoo.com

Sama- Resource Group for Women and Health, is a Delhi based women's group working from a larger perspective that links women's well-being with issues not only of health, but also those integrated with livelihood, violence (societal, familial, communal and medical), and all other issues that affect people's lives, especially those of women. Sama works closely with tribal, dalit and other marginalised communities and has made interventions through various activities like Community Based Training, Action Research, Advocacy and Material Production.
Sama is an active member of Jan Swasthya Abhiyan (Indian Chapter of People's Health Movement) and is part of the Autonomous Women's Movement.



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